Europe


Iceland
North Atlantic Ocean
Sweden
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Russia
Norway
St. Petersburg
Estonia
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Ireland
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The Netherlands
Belarus
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Czech Republic
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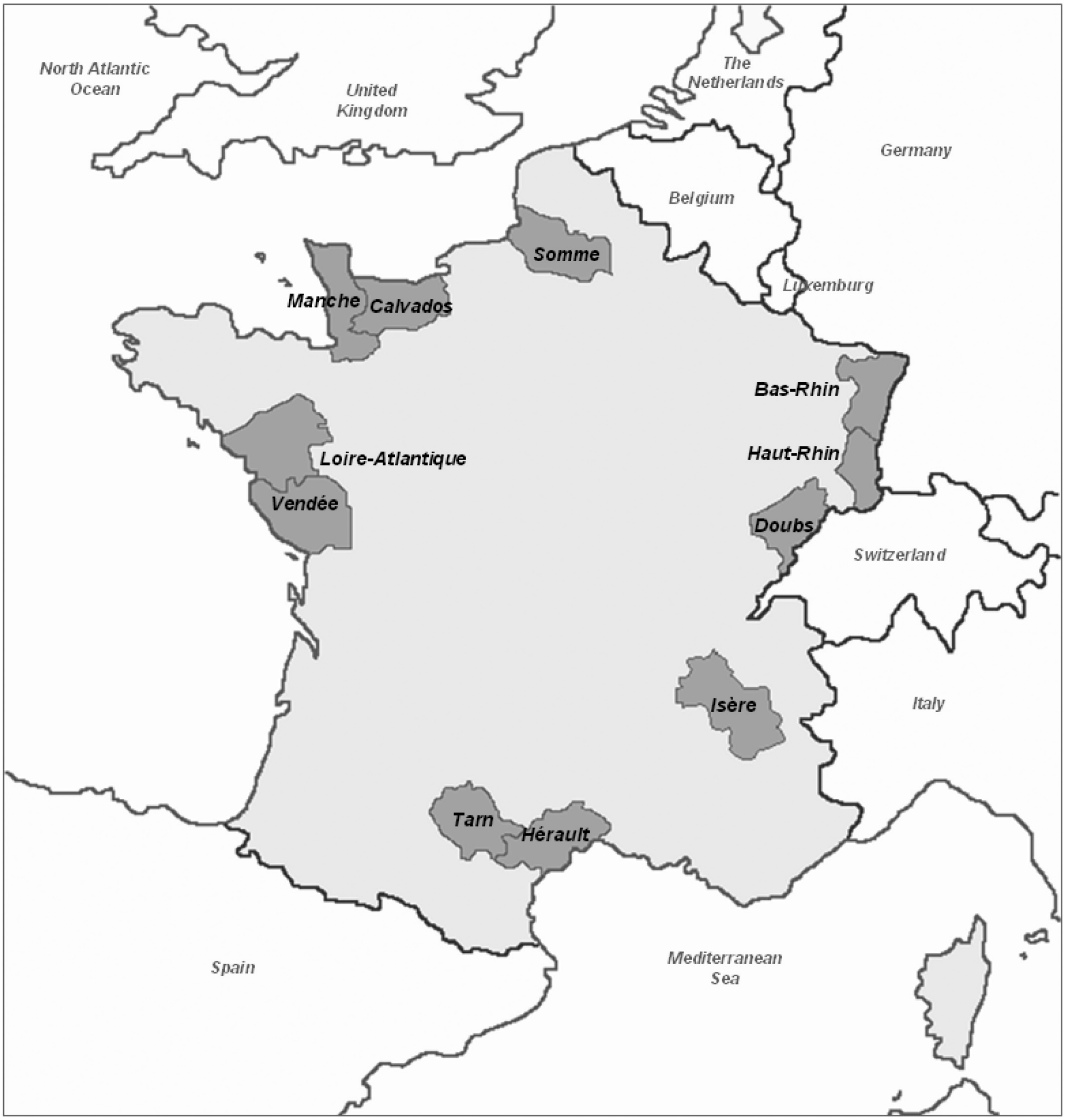
Malta

Central and Western Europe

France


North Atlantic Ocean
United Kingdom
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Italy


Germany
Austria
North East Cancer Surveillance Network
Hungary
Switzerland
Slovenia
Sondrio
France
Brescia Province
Veneto Region
Croatia
Biella Province
Milan
Torino
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Ferrara Province
Parma
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Modena Province
Romagna Region
Genoa Province
Florence
Macerata Province
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Ragusa Province
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Portugal and Spain

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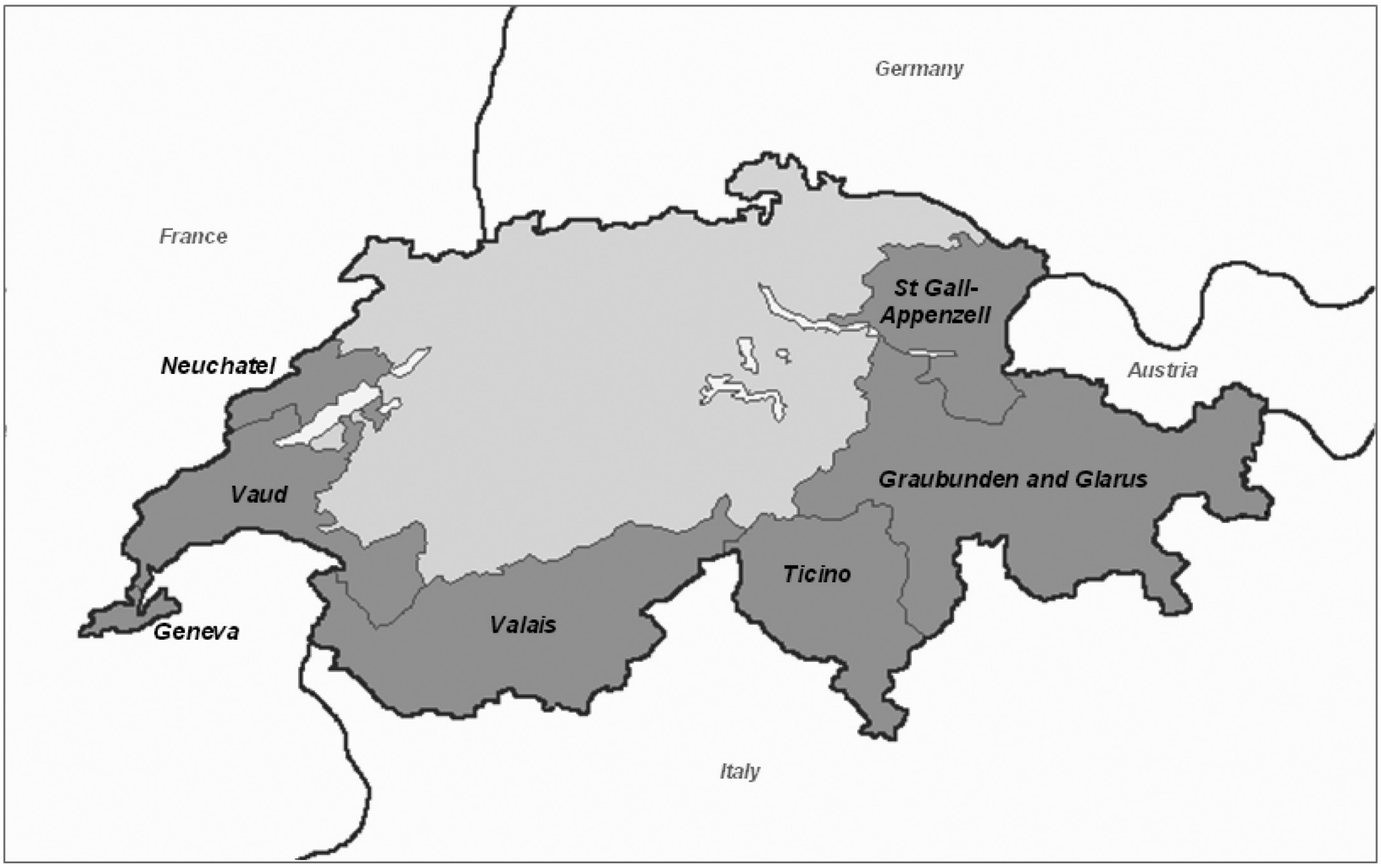


United Kingdom and Ireland

Austria

Registration area

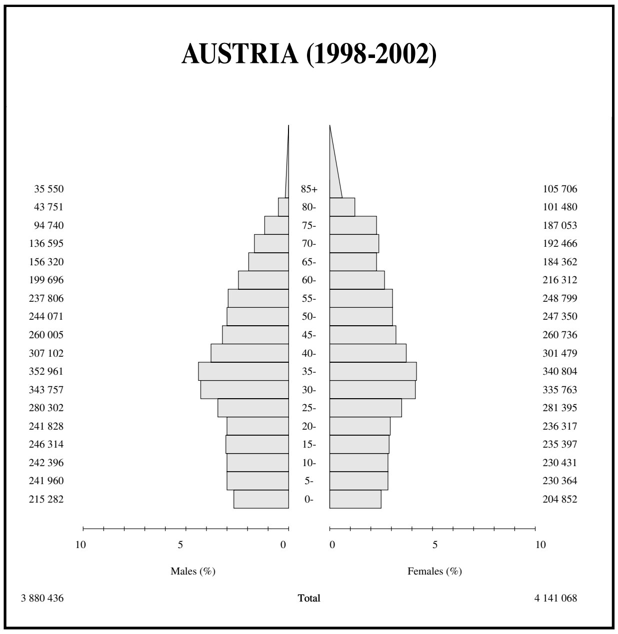
The Austrian National Cancer Registry covers the whole population of Austria, approximately 8.3 million (2007) inhabitants. About 90% of the Austrian population are Austrian citizens; other nationalities and/or ethnic groups include Turks, Serbs, Germans and Croatians. Approximately 15% of the population are foreign-born. More than 80% of the population are Catholic, and about 5% are Protestant. Another 5% are part of Islamic, Israelite and other Non-Catholic denominations.

Austria is divided into 9 provinces. The population is distributed as follows. Most of them reside in the provinces of Vienna (19.5%) and Lower Austria (19.2%), followed by Upper Austria (17.1%), Styria (14.7%), and Tyrol (8.4%). The lowest population can be found in Salzburg (6.4%), Carinthia (6.9%), Vorarlberg (4.4%) and Burgenland (3.4%).

The Austrian territory covers 83 871 km^2 of which 2/5 is permanently habitable. The country is characterised by a diversified geographical situation.

Cancer care facilities

A nationwide social security system covers 98% of the Austrian population. For inpatient treatment about 275 hospitals are available. More than two thirds of Austrian hospital beds are maintained by 133 public hospitals. Four of these hospitals are university hospitals, located in Vienna, Graz, Salzburg and Innsbruck. More than thirty hospitals run departments specialising in cancer treatment; many include a radiotherapy department.



Registry structure and methods

The Austrian National Cancer Registry is located in Vienna and is operated by Statistics Austria, the former “Österreichisches Statistisches Zentralamt”. According to the Federal Statistics Act 2000 (Bundesstatistikgesetz 2000) the Austrian government appointed Statistics Austria as the national provider of various statistics. The government finances all statistics prescribed by this law (including cancer statistics). Altogether 13 people are directly involved in the cancer registry workflow. Some of them work part-time or are involved in other projects as well, which results in 9.4 FTE.

Preparatory work for the cancer statistics was done by the Austrian Cancer Society, which led to a legal basis for cancer registration in 1957 (Krankenanstaltengesetz). Since 1969 a more detailed law (Krebsstatistikgesetz) obliges hospitals to report every cancer case to Statistics Austria. Population-based data collection started only one year later. Hospitals fill in a form providing personal data, topography, histology and behaviour of the tumour as well as the incidence date. The stage of the tumour at diagnosis and the first treatment are also reported. Files are increasingly now transmitted electronically (via disk or secure FTP).

Four Austrian provinces run their own regional cancer registries. Information on every cancer case is collected in close cooperation with the main hospital of the respective area and is electronically processed. The information is forwarded to Statistics Austria on a regular basis.

All invasive and in-situ tumours are registered, and topography, morphology and behaviour are coded to ICD-O-3. The coding is done centrally in Vienna apart from the codes assigned by the Tyrolean Cancer Registry are accepted separately.

All incoming data are stored in a database that performs data checks at the point of data entry. These data checks are based on the IARC CHECK program, broadened at the national level. IARC/IACR rules for classifying multiple primaries are implemented as well. Multiple notifications for the same person are identified using the full name, date of birth, sex and address as well as social security number. For the quality control and assessment of completeness, electronic data of pathology laboratories and of various study groups are used.

The causes of death statistics are available electronically and are used for passive follow up and generating DCN cases. All death certificates mentioning cancer are available for the registry as paper forms as well, and are traced back when the patient died in a hospital.

Interpreting the results

For the whole of Austria opportunistic screening is carried out for cervix, breast and prostate. For some regions organised screening is carried out for prostate and large bowel. A regional comparability study of the data is currently underway.

Use of the data

The registry publishes data annually since 1970 in the yearbook on health statistics. Tables printed in this annual report show incidence rates broken down by primary site, stage, sex, age and region. In 2005 a publication contrasting incidence and mortality data was released. In 2006 the scope was further enlarged when it was published on the Internet. A special analysis of survival for colorectal cancer was published in 2006 as well.

Highly aggregated data are available for all interests. Medical Universities, the Gesundheit Österreich GmbH (GÖG), and cancer study groups are provided with data, which are at a lower aggregation level but still anonymous.

Source of population

The data are estimated by Statistics Austria, based on census data 2001 and data provided by the Central Population Registry.

Multiple primary rules used

IACR rules (2004) on historical data.

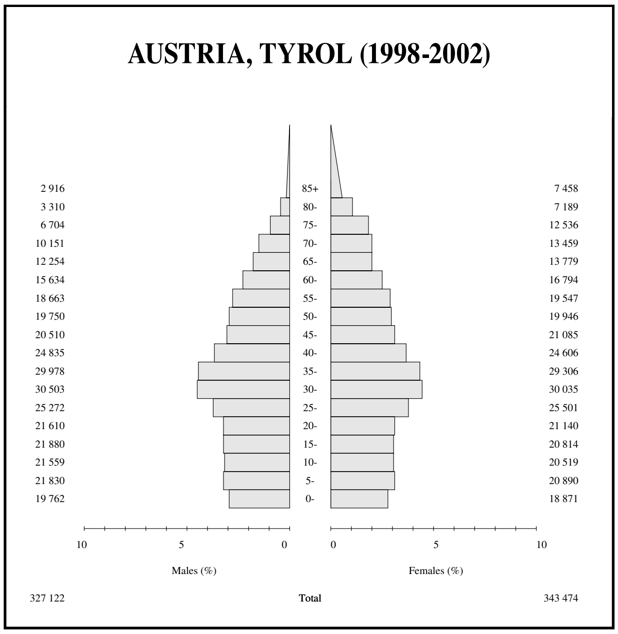
Austria, Tyrol

Registration area

Tyrol is one of nine provinces in Austria, and is situated in the west. The area covers 12 648 km²; only some 12.5% is habitable. The average altitude of the habitable regions is about 740m. Nearly 20% of the population lives in one town with more than 100 000 inhabitants (the capital Innsbruck), the rest in smaller towns (less than 15 000) and in some 260 villages. Nine percent of the people are from foreign countries, mainly from the former Yugoslavia and Turkey. About 90% are Roman Catholics. The main occupational groups are personal services (32%), commerce and traffic (22%), industry and trade (22%) and tourism (10%), with some 6% unemployed.

Cancer care facilities

Medical facilities are provided by Innsbruck Medical University (offering both basic facilities for Innsbruck and special facilities for the whole province), nine local hospitals in the rural districts and two semi-private hospitals in Innsbruck. All diagnostic and therapeutic services for oncological patients are provided in the country. Most pathology diagnoses are done by one main institute in Innsbruck and five smaller pathology laboratories. Radiotherapy is offered by one Department of Radiotherapy at Innsbruck Medical University and by a radiotherapy unit within the Department of Gynaecology of Innsbruck Medical University. Chemotherapy is provided by all hospitals. For some cancer sites (leukaemias and lymphomas, head and neck cancer, ovarian cancers, and advanced melanomas) most patients are treated at Innsbruck Medical University. Treatment outside the country is rather rare. Tumour boards have been installed in the last years, but until now did not cover all cancer patients.



Registry structure and methods

The Cancer Registry of Tyrol commenced operations at the end of 1986, and has been population-based since 1988. Since 1969 there has been a law obliging hospitals to report every cancer case to the Austrian Federal Bureau of Statistics. In addition, local registries are responsible for cancer registration in some provinces.

The Cancer Registry of Tyrol is a department within and funded by the TILAK, an organisation managing the university hospital of Innsbruck and some smaller hospitals in the Tyrol. The registry is staffed by a part-time epidemiologist, a full time registrar and one part-time registrar, and data entry clerks as needed.

All hospitals are obliged to report cancer cases. Most departments fill in a form consisting of personal data, incidence date, most valid basis of diagnosis, topography, histology, behaviour, staging and summary of first treatment. All pathology diagnoses concerning cancer and all death certificates are sent to the registry.

Multiple cancers are recorded separately at the request of the physicians, but the IARC rules are used for reporting.

Follow up information is based on probabilistic record linkage between the incidence data and all-cause mortality data for the province of Tyrol. Coding is done by one trained person in cooperation with a pathologist.

Programs for checking personal data were developed within the registry. Lists generated are checked manually, and if there are queries the local communities are contacted. The cancer data are checked using IARC Tools. For formal evaluation of completeness, since 2003 we have applied the Bullard method using a program developed by the Thames Cancer Registry. Besides extensive plausibility checks, no formal evaluation of accuracy has been done to date.

Interpreting the results

The population in the province is stable, and there have not been changes in the structure of the medical services. The organisation of the registry has not changed in the last ten years. PSA tests were introduced in 1988/89 and since 1993 have been offered to all men aged 45–74 free of charge; more than 3/4 of all men in this age group had at least one PSA test in the last decade. There is also a spontaneous mammography programme which has had some influence on breast cancer rates. In addition, Pap smear tests and haemoccult tests are offered free of charge, and dermatologists organise early detection activities for melanomas every spring. We have no knowledge of unusual environmental or occupational exposures in Tyrol that could influence cancer incidence figures on the population level besides high radon exposure in a small village with a population of 2800.

Use of the data

Annual reports have been produced since 1988. Besides usual figures, the report also includes staging information, regional distribution and relative survival rates. Reports are distributed to key decision makers and are accessible online from our website. The data are widely used by physicians (especially from Innsbruck Medical University). Quality improvement programmes at the department level make use of survival rates. Survival data have been published within the EUROCARE study group.

Besides routine reports, the registry has been involved in a study of radon exposure and lung cancer. Main scientific work is concentrating on analysing time trends, mainly for prostate cancer and breast cancer.

Source of population

Official population data collected by Statistics Austria. In 2001, the population data were extracted from the census file; in the other years the population figures have been estimated in usual way.

Multiple primary rules used

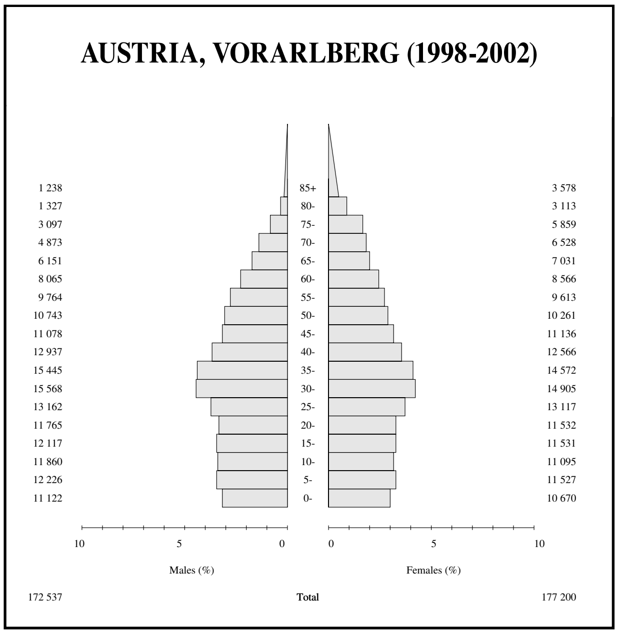
IACR rules (2004) on CI5 IX period.

Austria, Vorarlberg

Registration area

Vorarlberg is the westernmost of the nine federal states of Austria. It borders Switzerland, Germany, Liechtenstein and the Austrian federal state of Tyrol (19% of the border). Lake Constance comprises 8% of the border between Austria and Germany and Austria and Switzerland. Vorarlberg covers 2601 km^2, of which only 21% are habitable. 90% of the area is mountainous. Vorarlberg lies between 9° and 10°E and 46° and 47°N.

The total population of 351 570 (177 971 females, 173 599 males per census 2001) lives in 96 communities, five of which are cities; 51% live in communities with more than 10 000 inhabitants, 43% in communities with 1000 to 10 000 inhabitants and the others in smaller communities. The Rheintal (Rhine River valley) and Walgau are home to 81% of the population. The population density in the Rheintal (permanently settled area) is 1125/km^2, whereas the population density for the whole federal state (permanently settled area) is 620/km^2. Life expectancy at birth is 75.8 for males and 82.6 for females (2001). Inhabitants from foreign countries make up 14.5% of the population: 5.2% from Turkey, 4.6% former Yugoslavia, 2.8% from Germany, and 0.4% from Switzerland. 87.2% are Roman Catholics, 2.8% Protestants, 4.7% Muslims, 3.3% other denominations. The main occupational groups are: services (55.4%) and industry and trade (42.7%). The 2001 unemployment rate was 4.3%. See http://www.vorarlberg.at for further information.



Cancer care facilities

5 public hospitals and 2 private hospitals cover most medical needs. In special cases patients are sent to hospitals in other areas, mostly the university hospital in Innsbruck, Tyrol. Cancer treatment is provided by every hospital. There is only one Radio-Oncology department in the province, in Feldkirch. Hohenems hospital has recently opened a palliative care department.

Registry structure and methods

The Cancer Registry of Vorarlberg was founded in 1978 by the Pathology Department at Feldkirch hospital. Electronic data processing was introduced in 1981.

In 1968 a cancer registration law was passed in Austria, obliging hospitals to report every cancer case to the Federal Bureau of Statistics. In addition to this federal registry, local cancer registries exist in some federal states. In Vorarlberg the cancer registry is part of the “Arbeitskreis für Vorsorge und Sozialmedizin (aks)”, a non-profit organisation founded in 1964, working on behalf of the local government in the field of health promotion, preventive medicine and social medicine. Per Vorarlberg government decree, hospitals are required to send their records to the local cancer registry, from where they are forwarded to the Federal Bureau of Statistics. The main source of the data is the Institute of Pathology (histological, cytological and necropsy diagnoses). The data are transferred to the cancer registry and compared to data already registered. From there a registration sheet (including the pathology diagnosis) is sent to the hospital for further information. In cases with no pathology diagnosis the hospitals report the cases directly. The radiooncology department, which tracks each patient, also sends data to the registry. In general, multiple notifications are received for one cancer phase. Persons are identified by name, date of birth, sex, address and (since 1995) social security number. A sophisticated program developed by the Cancer Registry of Tyrol establishes links between various records. Multiple cancers for a person are recorded separately. Follow-up is confined to date of death.

Topography and histology are classified according to ICD-O-DA (German edition). Coding is done by a trained person in cooperation with a pathologist and medical doctor. The first quality inspection is performed by the medical manager before data is entered. In addition, IARC check programs and plausibility checks established by the Cancer Registry are applied periodically.

The only pathology institute in our region provides the first information on cancer at primary histological diagnosis and on autopsy reports. Clinicians from the clinical departments supplement the remaining data. Aks staff merge the data into the cancer registry. Completeness is examined by comparison with all hospitals’ discharge diagnoses. We organise team sessions on a regular basis with participation from responsible persons from the aks.

Interpreting the results

The population in the province is stable and there have been no changes in the medical services structure or in availability of diagnostic or treatment services. Case definitions and coding did not change in 1998–2002. Well-organised preventive care and early detection programs have been available in Vorarlberg for many years. In 1998–2000, 37% of women and 32% of men took part in health checks (including hemocult tests) and 45% in gynaecological exams (including Pap smear). Mammography screening has been active since 1989.

Use of the data

Annual reports are made to the government health department. The data are used for evaluating local cancer screening programs, such as early breast cancer detection, cervical cytology and colon adenoma. In Vorarlberg, health checks (*Gesundenuntersuchungen*) are very common, so the cancer registry also documents dysplasia and adenoma of the colon as cancer risks. Incidence data for the Cancer Registry of Vorarlberg between diagnosis years 1996–2000 have appeared in a publication entitled *Cancer Mapping in Alpine Regions 1996-2000: Trentino, South Tyrol, Carinthia, Tyrol, Vorarlberg*. Data are linked and used for publications and scientific reports known as the Vorarlberg Health Monitoring and Promotion Programm (VHM&PP). For further information see: http://www.aks.or.at and search "Health Monitoring & Promotion".

Source of population

The data are estimated by the Institute of Statistics in the Government of Vorarlberg, based on census data from 2001.

Multiple primary rules used

IACR rules (2004) on CI5 IX period.

Belarus

Registration area

The Belarussian Cancer Registry covers the population of Belarus, which occupies 207 600 km^2. The population in 1999 was 10 179 121 (males 46.6%, females 53.4%, urban 70.3%).

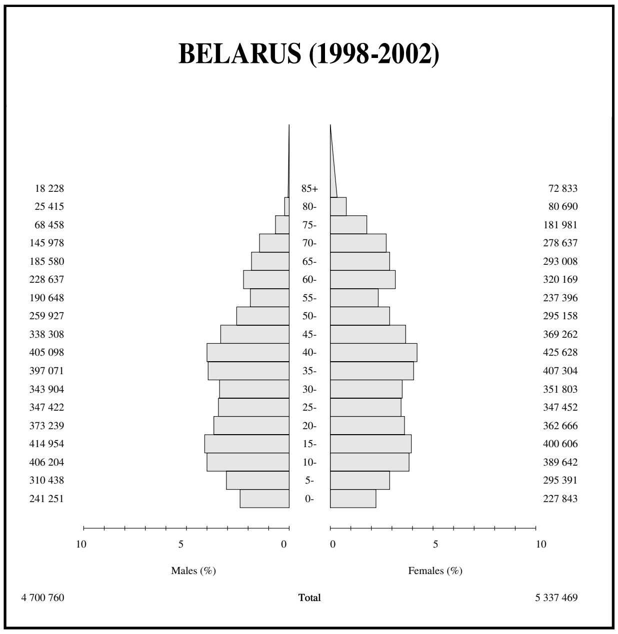
Cancer care facilities

The main treatment facilities are the 12 oncological dispensaries, which combine outpatient and inpatient clinics, and an Institute for Oncology and Medical Radiology.

Registry structure and methods

Cancer registration is mandatory and has been carried out according to the directive of the Ministry of Public Health of the USSR since 1953. However, until the beginning of the 1970s, it was performed on the basis of obligatory official statistical reports, and there was no computer database with individual information on cancer cases.

The Belarussian Cancer Registry includes complete individual information on cancer cases since 1978, but for the period 1978–1985 there are no personal identifiers such as name and address. In 1985–1988 a computer system was gradually set up in the oncological dispensaries, which allowed long-term continuous data collection for each patient and easier follow-up. Since 1991 this system has functioned on personal computers in all the Belarussian oncological dispensaries and the Institute for Oncology and Medical Radiology. Since 1999 new computer system was introduced based on ICD-10 and ICD-O-2 morphological classification.



The Belarussian cancer registry has been located in the Belarussian Centre for Medical Technologies, Computer Systems, Administration, and Economics of Public Health in Minsk since 1992.

In Belarus, the majority (about 80–85%) of cancer patients are diagnosed and treated in the oncological dispensaries and the Institute for Oncology and Medical Radiology, which is responsible for the registration of cancer cases for Minsk oblast (region). This makes data collection significantly easier. The 12 oncological dispensaries and the Institute for Oncology and Medical Radiology are responsible for registration of all cancer patients permanently residing in their service area, and regional sub-registries of the Belarussian Cancer Registry are maintained in the oncological dispensaries and the Institute for Oncology and Medical Radiology.

Most information is entered onto computers directly from patients' medical records (outpatient medical card and history of disease) stored in the dispensaries and the Institute for Oncology and Medical Radiology. Extracts of medical documents and special notification forms are also obtained from the Institute for Oncology and Medical Radiology, the Children's Oncological and Haematological Centre, Centre for Thyroid Tumours Pathology, Institute for Neurology, haematological hospitals, hospitals with cancer beds, and out-patient clinics, where cancer is diagnosed and treated. Pathologists must also complete and send a notification if they incidentally diagnose cancer as a result of an autopsy.

Death certificates are checked monthly by the personnel of the oncological dispensaries and the Institute for Oncology and Medical Radiology in regional state statistics departments for any mention of cancer. Information found is checked against the database in the dispensary. For each cancer case not found in the database additional information is requested from the institution, which issued the certificate.

In-situ cancers are registered but are not included in the cancer statistics.

Primary multiple tumours are registered as separate cancer cases if they appear (simultaneously or at a later time) in different organs or different parts of the same organ (including skin); each tumour is entered into the database separately according to the 4-digit ICD-9 code. The records have the same unique key and may be analysed together if desired.

Interpreting the results

In 1986 the Chernobyl accident resulted in radiation exposure to about 20% of the Belarussian population. After 1991, a high increase in the number of thyroid cancers in children, related to I^{131} irradiation of the thyroid gland, was observed.

Use of the data

The Belarussian Cancer Registry submits official statistical reports to the Ministry of Health annually, including data on cancer incidence, mortality and treatment in Belarus, as well as the statistical collection *Malignant Neoplasms in Belarus for a Decade*, highlighting trends and changes.

Source of population

Annual populations are estimates, calculated by the State Statistical Department on the basis of the 1999 census, making allowance for births and deaths, and migration into and out of the registration area. Migration data are annually provided by the Ministry of Internal Affairs to the State Statistical Department.

Multiple primary rules used

IACR rules (2004) on CI5 IX period.

Notes on the data

The Editors recommend that some care be taken in the interpretation of these data; see Chapter 5 (Categorisation).

Belgium, Antwerp

Registration area

The Antwerp Cancer Registry covers the province of Antwerp in the north-west of Belgium. Almost half of its population of 1.6 million inhabitants is concentrated in and around the city of Antwerp. The western half of the province has a high urbanisation grade, whereas the eastern half of the province is mainly rural.

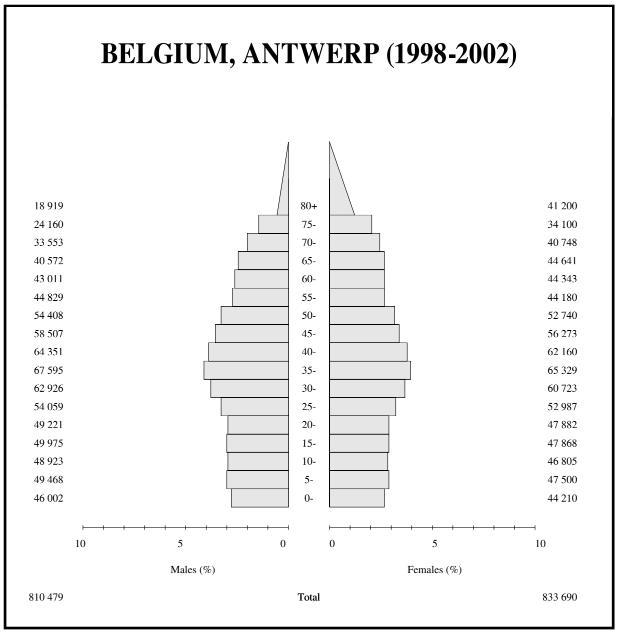
Cancer care facilities

The province of Antwerp has 36 hospitals, of which 6 have an oncology centre. Five hospitals in the registration area have radiotherapy departments

Registry structure and methods

The ACR is located at the Department of Epidemiology and Community Medicine of the University of Antwerp and is funded by the Flemish government.

The staff of the registry consists of a head medical officer, an epidemiologist and 7 registration workers. The registration process is based upon the Dutch cancer registry, characterised by active case finding, data collection and coding by the registration workers in all hospitals and the major private pathology laboratories of the province. There is no access to death certificates; therefore these are not used for case finding.



Interpreting the results

Coverage of the entire province was not complete until the incidence year 2000, when all hospitals in the registration area participated in registration; under-registration in 1998 and 1999 may be estimated around 5%. Some organised screening programmes exist for cervical, breast and prostate cancer; however, these data are not being used directly for case finding.

Use of the data

The ACR reports crude, age-specific and age-adjusted (ESR) incidences annually; moreover, each participating hospital obtains an annual report on all of its own diagnosed and/ or treated cancer patients. Registration data are provided for research purposes to internal as well as external institutions.

Our data are used directly by local health authorities, for evaluation of screening programs and indirectly: hospitals report to the federal health department using cancer registration data.

Source of population

Official data from population register, provided by the administration.

Multiple primary rules used

IACR rules (1990).

Notes on the data

The Editors recommend that some care be taken in the interpretation of these data; see Chapter 5 (Categorisation).

Belgium, Flanders

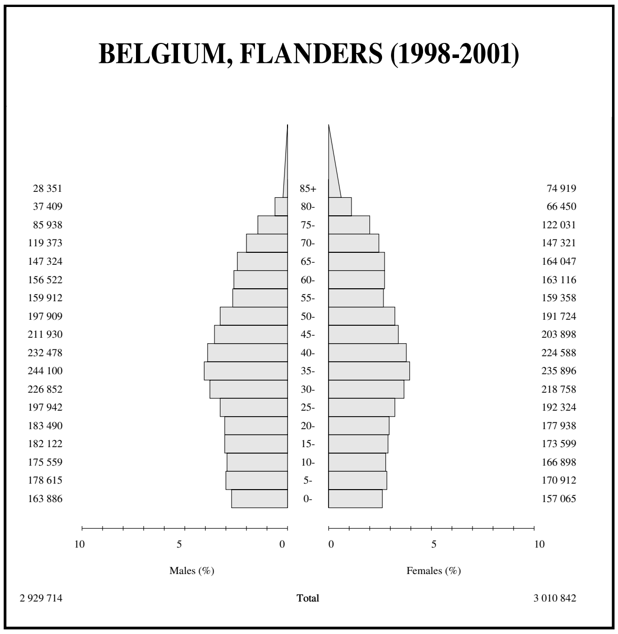
Registration area

Flanders is situated in the north of Belgium and comprises 5 provinces. The estimated mid-year population for 2000 was 5 946 402, of whom approximately 5% are foreigners. The mean population density is 439 inhabitants per km².

In 2000 people over age 60 made up 22.2% of the total population, with 11.7% older than 70 years of age. The life expectancy at birth was 76.0 years for men and 81.9 years for women.

Cancer care facilities

In 2000 there were 3.1 physicians per 1000 inhabitants and 5.1 general hospital beds per 1000 inhabitants. The medical care institutions are easily accessible and medical care is provided by 116 general hospitals.



There are no specific cancer hospitals or regional cancer centres. Oncological care and radiotherapy are provided within general and university hospitals. For the whole country in 2000, 163 radiotherapists and almost 287 pathologists were registered at the Ministry of Health and Social Affairs. In 2000 there were 25 radiotherapy services in Belgium, of which 14 were located in the Region of Flanders.

More than 99% of the population living in Flanders are affiliated with one of the National Health Services for mandatory medical insurance. All of these National Health Services are grouped in a National Health Insurance System.

Although there were no regional or national organised screening programs for cervical nor breast cancer until June 2001, many women did have a Pap smear and mammography taken regularly at that time. In June 2001 a national breast cancer screening program was launched for women aged 50–69 years. There are also local initiatives for screening of cervical cancer and malignant melanoma. Opportunistic PSA testing has been used increasingly.

Registry structure and methods

The Belgian Cancer Registry is subsidised by the National Ministry of Public Health and by the Ministries of Public Health of both communities (French and Flemish). Since 1983 the National Health Services have been collecting data on newly diagnosed malignant tumours among their contributing members and families. In Flanders, from 1996 onwards, different cancer registration systems, essentially the provincial cancer registry in Antwerp (AKR), the provincial pathology cancer registry in Limburg (LIKAR), the bronchus carcinoma registry for Flanders (VRGT), some hospital cancer registries and almost all pathology laboratories, have been integrated in a cancer registration network. In 2003 the Flemish staff of the cancer registry consisted of 2 data managers, a part-time pathologist and a physician coordinator.

Both active and passive data collection methods are used in this network, but all data are provided electronically to the Belgian Cancer Registry in a predefined structure. Due to privacy regulations only encrypted data are allowed to be transmitted. The personal identifiers are encrypted by the same procedure at the hospitals, the National Health Services and the pathology laboratories.

All invasive and *in situ* tumours are registered. Topography, morphology, behaviour and differentiation are coded to ICD-O-2. In Flanders the majority of the pathologists work with CODAP codes which are translated automatically to ICD-O-2 by means of a computer program. For staging of tumours the TNM classification is used. The IARC rules for classifying multiple primaries were adapted slightly.

All incoming data are checked at the Belgian Cancer Registry with a control programme based on the rules of the IARC-check program and supplemented with other controls developed at the registry. Multiple notifications for the same tumour are linked according to the encrypted personal identifier at the Cancer Registry and summarised by automated decision rules. A significant number of cases are resolved manually.

Death certificates are also transmitted to the cancer registry, but they are anonymous and do not permit any trace-back procedure. They can only be used as an additional check for date of death and the cause of death. The independent data set method was used in 2005 to evaluate the completeness of the cancer registry (year of incidence 2000–2001). The completeness was estimated to be 98.2%.

Use of the data

Annual incidence data by sex, age, site and geographical units are routinely produced. Detailed data for the major cancer sites are analysed in separate chapters that are published and distributed. Survival data were published for the first time in March 2006. Data are also displayed on the website of The Belgian Cancer Registry and www.tegenkanker.be/kankerregistratie. Numerous requests for data are provided to research workers, clinicians, health care planners, paramedics and the general public.

Source of population

1997–2001: Mid-year population estimate. Source: FOD Economie – Algemene Directie Statistiek en Economische Informatie.

Multiple primary rules used

IACR rules (2004) on CI5 IX period.

Bulgaria

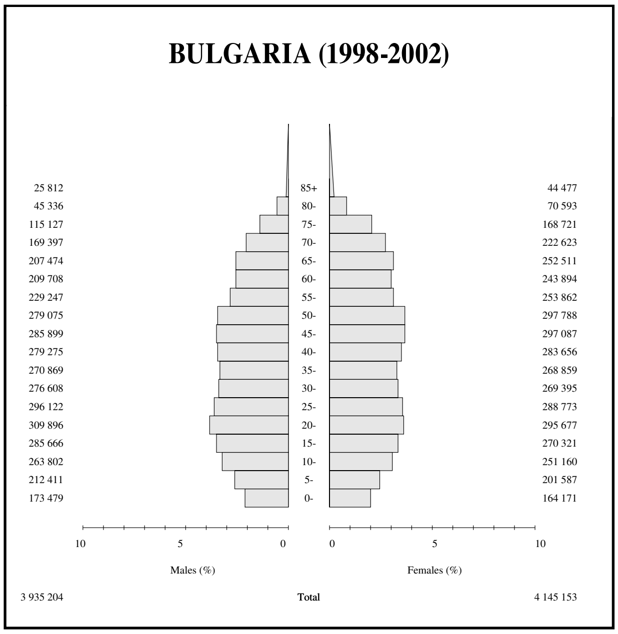
Registration area

The Bulgarian National Cancer Registry (BNCR) covers the whole population of Bulgaria. The population at the most recent census (1 March 2001) was 7 932 984. About 70% of the population (<6 000 000) lives in urban areas. The predominant religion is Eastern Orthodox Christians (85%); 13% are Moslems and nearly 1% Catholics.

Cancer care facilities

Until 1989, medical care in Bulgaria was free. Private medical practice has been permitted since 1991. National Health Insurance was introduced in 2000. Health care is mostly public, including regional hospitals, university clinics, specialised hospitals and primary health establishments, supplemented by private practitioners and hospitals.

A specialised cancer network was founded in Bulgaria in 1952. It includes 13 Regional Oncological Centers (dispensaries), covering populations between 370 000 and 1.2 million inhabitants. Another part, National Oncological Hospital (NOH) is located in Sofia. The specialised cancer system provides prevention, diagnostic, treatment (radiotherapy, surgery, chemotherapy) and follow-up services for cancer patients. In 2000 a total of 27 526 physicians were engaged in healthcare activities, 471 of whom were physicians in oncological centres. Natioanlly there were 60 552 hospital beds, of which 2005 were in oncological centres.



Registry structure and methods

The Bulgarian National Cancer Registry, funded by the Ministry of Health, is part of the National Oncological Hospital. One physician, one statistician, one specialist in computing and six full-time clerks staff it. In each of the 13 dispensaries, there is a Regional Cancer Registry, usually staffed by one full-time physician and 2-3 clerks.

The BNCR uses active and passive methods of data collection. Compulsory registration of malignant diseases in Bulgaria was introduced in 1952. Every physician is required to send a "rapid notification" to the Regional Oncological Centre for each newly diagnosed or suspected cancer case, death from a malignant neoplasm, and since 1975 for cancer *in situ* as well. The rapid notification system was updated in 1992. From 1993 cancer patients have been followed up by type of treatment and date of death as well. In 2000 new items and codes were introduced according to European Network of Cancer Registries recommendations.

Other sources of information on cancer patients are medical records from oncological centres and other specialized hospitals, university clinics, primary health establishments (outpatient and inpatient), pathology and haematology laboratories, death certificates, Central Population Register, hospices, etc. Dispensary clerks frequently visit all hospitals with wards diagnosing or treating cancer patients, pathological laboratories, etc. to add to the rapid notification data.

In January 2006 the ICD-10 was introduced in Bulgaria; all cancer cases since 1993 have been recoded. To improve the registration system a check of the Central Population Register was made for all cases who died after 1998.

For registration of malignant neoplasms a new software product has been developed. In each regional register trained clerks, under the supervision of physicians, code the data. Processing includes verification of completeness, checking for duplicates by name, identification number (PIN), address and diagnosis, consistency and compliance between clinical and morphological diagnosis, computerised checking and correction of coding and typing errors. Histology is coded according to ICD-0-2. Benign lesions and those of uncertain behaviour are not registered. The BNCR uses IARC Tools Version 2.03 (2006) and DEPedits Version 1.00 (2006). Legislation for data confidentiality is not yet available in Bulgaria; thus each patient is assigned a unique ID number.

In the registry we currently compare (for completeness and accuracy) and evaluate the data between: incidence and mortality data; incidence data between 28 districts in Bulgaria and over time; incidence data between Balkan countries, etc. Every three months we receive information for all deaths from the Central Population Register in Bulgaria. This comparison is published in *Lung Cancer: Current Status and Perspectives, September 2005*; *Balkan Union of Oncology, Proceedings/ Educational Book, 5th Congress*, etc.

Interpreting the results

Despite active and passive methods of cancer registration there is possible nonregistration of cancer cases mainly among elderly people and among inhabitants of the rural areas. There are some omissions in coding cause of death (metastasis instead of primary site) as well, leading to a discrepancy between incidence and mortality data, especially in liver cancer, esophageal cancer, etc.

Bulgaria now has opportunistic screening for breast cancer and cervix uteri cancer funds from the National Health Insurance Fund. A Strategy for Prophylactic Oncological Screening in Bulgaria was created for 2001–2006. It includes breast cancer, cervical cancer and prostate cancer. The Strategy was accepted by the Council of Ministers on 23rd of April 2001 but it was not undertaken for various reasons (faults in program organisation, screening tests, interpretation of the results, etc.). PSA testing is not common.

Use of the data

The BNCR annually publishes cancer incidence data in Bulgaria. The data available in the BNCR are used for epidemiological studies, reports, communications and the like. Bulgarian policymakers use cancer registry data for planning or evaluation of health services.

Source of population
Official estimate. Source: The National Statistical Institute (http://www.nsi.bg).

Multiple primary rules used
IACR rules (2004) on CI5 IX period.

Notes on the data
The Editors recommend that some care be taken in the interpretation of these data; see Chapter 5 (Categorisation). This registry has the lowest histological verification rate in the monograph.

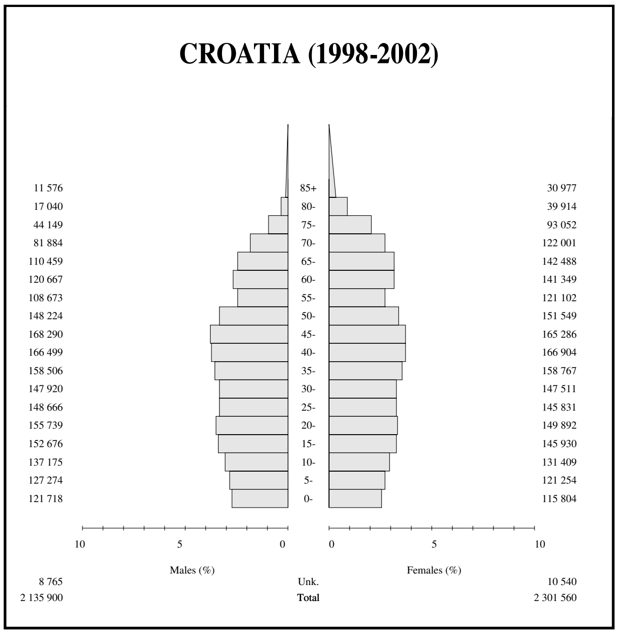
Croatia

Registration area

The Croatian National Cancer Registry covers the whole country of Croatia. The Republic of Croatia is situated along the eastern coast of the Adriatic Sea and covers an area stretching up to the last slopes of the Alps and deep into the Pannonian Valley to the banks of the Drava and Danube Rivers. Croatia is divided into three geographical regions: the Mediterranean, the Mountainous, and the Pannonian. Roman Catholics account for 87.8% of the population. Administratively, the country is divided into 20 counties and the City of Zagreb.

Cancer care facilities

In 2003, the health service entry points are 2372 primary care physicians, i.e. general practitioners, gynaecologists and paediatricians. There were 23 general hospitals. In addition, there were 12 clinical and two clinical teaching hospitals, and some specialised hospitals, of which one was dedicated to oncology. Most health institutions admitted oncology cases, but the main regional oncology centres with a full range of services are located in the clinical hospitals in Zagreb, Split, Osijek and Rijeka.


CROATIA (1998-2002)

Registry structure and methods

The registry is part of the Chronic Disease Epidemiology Service at the Croatian National Institute of Public Health in Zagreb, the capital of Croatia, and is funded by the Ministry of Health and Social Welfare. A medical doctor specialist of epidemiology, a senior statistician, a technician and two data entry clerks staffs the registry full-time. Software support is provided by an external IT firm.

The basic notifications are from hospital discharge, pathology reports and primary care. Additional information is derived from every official death certificate that mentions cancer. Notifications include the name of the health providers (hospital or physician) so that they can be contacted for further information. Hospital discharge records in electronic format are used as a supplementary data source. Topography is coded in ICD-10, and morphology in ICD-0-2 classification.

Interpreting the results

There have been no organised population-based screening programmes in Croatia in the period 1998–2002. National population-based screening programmes were introduced in 2006 for breast cancer and in 2007 for colorectal cancer. However, opportunistic screening for cervical cancer has been going on since the 1960s, and the number of Pap smears taken yearly is increasing, as well as the number of mammographies. Opportunistic screening by faecal occult blood test has been going on in some regions, while PSA testing is becoming more common, but only in patients with urological symptoms.

Use of the data

Cancer incidence data have appeared each year in an annual report (bulletin in Croatian and English) and in the Institute's joint annual report since 1976. Analyses and observed trends are published in medical journals, masters and doctoral theses, and presented in congresses and other scientific gatherings. Survival analyses of registered cancer cases in the periods 1988–1993 and 1994–1998 have been carried out.

The registry was created in response to the growing public health problem posed by cancer. Data on cancer incidence and mortality are used for planning and evaluation of preventive measures and healthcare services.

Source of population

Census 2001. Census of population, households and dwellings 31st March 2001, Release 2, 17th September 2003, Republic of Croatia Central Bureau of Statistics.

Multiple primary rules used

IACR rules (2004) on historical data

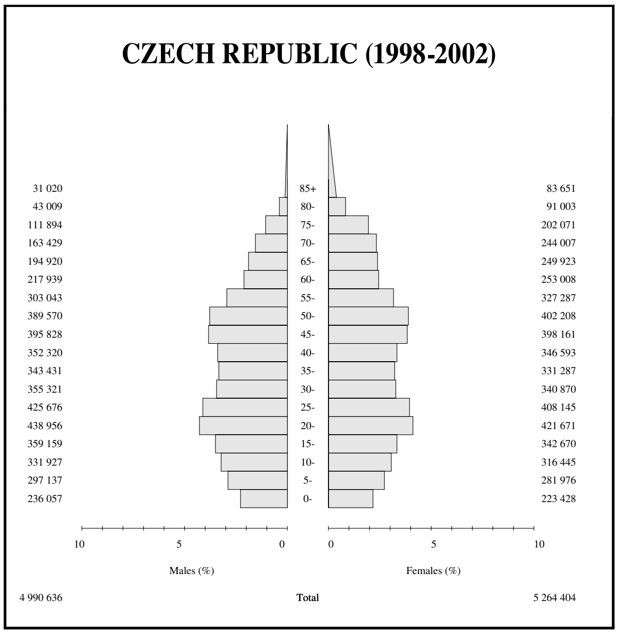
Czech Republic

Registration area

The National Cancer Registry of the Czech Republic is a territorial registry covering all residents of the Czech Republic, which lies in Central Europe. Mild climatic conditions do not vary markedly with geographical latitude over the territory.

The population of the Czech Republic is 10.2 million (2002). According to the 2001 Census more than 70% of the population is urban. A significant ageing trend in the population is accompanied by low fertility rates (during 1998-2002 total fertility rate was below 1.2). Life expectancy at birth was 72.1 years for males and 78.5 years for females (2002).

The population of the Czech Republic is ethnically homogenous. The majority of population (90.2 %) declared Czech nationality (Census 2001). The biggest ethnic minorities are Slovak (1.9 % of the whole population) and Polish (0.5 % of the whole population). Regarding religion, many are nondenominational (59.0%); the majority of believers (26.8% of the total population) were affiliated with the Roman Catholic Church.



Cancer care facilities

There is an extended network of health services in the Czech Republic. Oncological diseases are treated in specialised establishments in accordance with the kind of cancer. There are 83 outpatient establishments for clinical oncology, employing 112 physicians and 226 paramedical personnel. There are 39 outpatient radiotherapy departments with 117 physicians and 362 paramedical personnel. In the hospitals there are 11 departments of clinical oncology with 286 beds and 48 physicians, and 24 radiotherapy departments with 1185 beds, staffed by 113 physicians (as of the end of 2002).

Registry structure and methods

The National Cancer Registry of the Czech Republic (NCR) was founded in 1976 and connected with data collection on mortality from oncological diseases. However, cancer incidence has been registered since 1956. The NCR receives financial support from the Ministry of Health. Administrator of the NCR is the Institute of Health Information and Statistics (IHIS).

The National Cancer Registry of the CR itself has no regular staff. Programming is outsourced; data managing and analysis are done by three full-time employees of IHIS CR and two full-time employees of the Coordination Centre for Departmental Medical Information Systems (CCDMIS has an executive role in managing NCR). About 120 professionals are responsible for data entry (mostly hospital nurses) and about 80 physicians look after data entry and proper classification.

In the Czech Republic reporting of malignant neoplasms, in situ neoplasms and neoplasms of uncertain or unspecified behaviour is obligatory. The report is returned by the physician who diagnoses the neoplasm. Data collection is performed with the aid of Regional Units of the NCR, which collect the mandatory reports, histopathological reports, discharge reports, protocols on surgery, etc. These data are collated by the workers of the NCR Regional Units.

Collated data are transferred electronically to the Registry. All data are collected, processed and transferred to the central database using unified software with built-in online controls. Data are kept confidential in the recording and data transfer process. The central unit updates the Registry after checking and eliminating duplicates. This process is supplemented by annual comparison with the database of deaths run by the Czech Statistical Office; NCR also has access to the death certificate database, which is used for additional case-finding.

Apart from this statistical activity, patients are followed continuously (except non-melanoma skin cancer patients). Specialised follow-up (dispensary) health establishments return a mandatory check-up report for each case after 1, 2, 3, 4, 5, 7 and 10 years, then every five years and on the patient's death. The Regional Units employ physician cancer specialists and nurses on part-time contracts, mostly in addition to their practice in the field. The centre in IHIS has three specialists working directly in NCR activities.

Interpreting the results

The first organised screening programme in the Czech Republic was introduced in August 2001 for colorectal cancer. Women and men older than 50 years are involved in the colorectal screening programme. Nationwide organised breast cancer screening of women aged 45–69 was introduced in September 2002. Opportunistic screening for cervical cancer could influence incidence rates. In the Czech Republic PSA testing was introduced in 1990 and has been done routinely since 1992.

Use of the data

IHIS publishes a yearbook entitled *Cancer Incidence in the Czech Republic*, containing detailed data on incidence of neoplasms and mortality from cancer. Additional details (stage of disease, therapy) are analysed for 10 selected diagnoses. The Central Unit in IHIS processes additional data responding to about 50 special requests a year, from specialists as well as the lay public (media), and compiles additional special publications. Other publications using registry data are prepared by other specialists or organisations.

Although IHIS of CR is not involved in epidemiological research, data of NCR of CR are submitted to scientists (e.g. researchers in Masaryk Memorial Cancer Institute). One of the tasks of the National Oncological Programme (NOP) is to support continuity, stabilisation, modernisation and practical utilisation of the database for controlled preventive and diagnosis-treatment care in oncology. NOP was officially supported by President Vaclav Klaus and by Ministry of Health of CR. The politicians devote great interest in oncological data. Practical cancer incidence data are used to evaluate the quality of hospitals' services.

Source of population

Postcensal estimates. The population estimates for 1998–2000 are based on the 3 March 1991 Census and for 2001–2002 on the 1 March 2001 Census.

Multiple primary rules used

IACR rules (2004) on historical data.

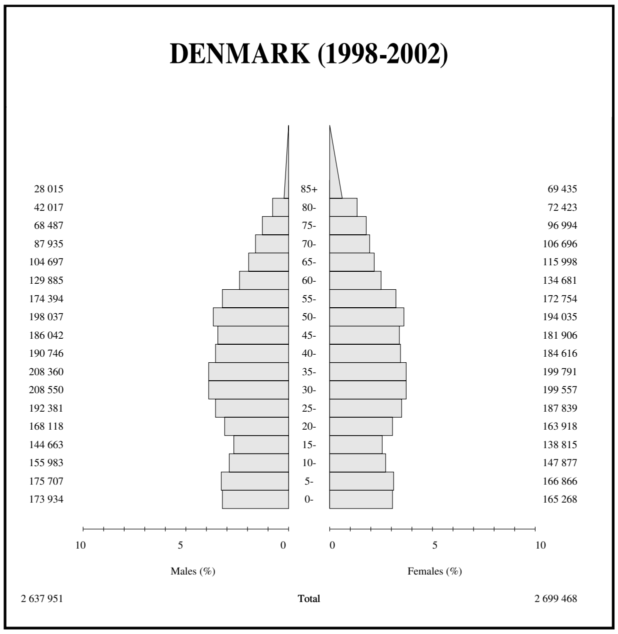
Denmark

Registration area

The Kingdom of Denmark, excluding Greenland and the Faroe Islands, covers 43 080 km^2 between latitudes 55 and 58° N, and longitudes 8 and 12°30′E. The mean population of Denmark was 5 340 000; it is of Caucasian stock and fairly homogeneous. Approximately one third of the population live in the greater Copenhagen area, 40% live in provincial towns of 10 000 to about 200 000 inhabitants, and the rest live in rural areas. Since 1968 all inhabitants have been given a unique personal identifying number, used in most registration systems, including the cancer registry. A central computerised population register keeps a continuously updated file of personal information on all inhabitants.

Cancer care facilities

The medical care system is organised into a private sector of general practitioners and specialists under contract with the National Health insurance, and a public sector operating hospitals under the authority of the counties and municipalities or the Danish State. Health care is provided free to all inhabitants. Cancer surgery is carried out both at general hospitals and at oncological centres. The hospital departments are serviced by 23 institutes of pathology. Non-surgical cancer treatment is partially centralised at five university hospitals with radiotherapy and oncology expertise and one regional oncological centre (Vejle Hospital). Almost the entire population is capable of reaching a specialised cancer centre within a few hours by ground transport.


DENMARK (1998-2002)

Registry structure and methods

The Danish Cancer Registry was founded in May 1942 as a nationwide programme to register all cancer cases in the population. Incidence figures are available from 1 January 1943. Registration is compulsory by administrative order as of 1 March 1987, today incorporated in the National Health Law. This order also covers Greenland, and a similar order was issued for the Faroe Islands by the Faroe authorities. Data from Greenland are not included in the Danish incidence figures, but published separately. Data from the Faroe Islands are not included in the Danish Cancer Registry. The registry was, until January 1997 administratively part of the Danish Cancer Society, but has since then been the responsibility of the National Board of Health. A close collaboration between the Cancer Registry and the Danish Cancer Society that holds the full and regularly updated copy of the cancer registry for research purposes has been established. The Cancer Registry operates under the law on public authorities registries with instructions established by the Ministry of Health and supervised by the National Data Protection Agency, whereas the Danish Cancer Society copy of the Danish Cancer Registry operates under the law on private registries also supervised by the National Data Protection Agency. Data extraction and requests for data for research projects external to the Danish Cancer Society must be forwarded to the Cancer Registry at the National Board of Health.

Upon receipt at the cancer registry, notifications are checked and coded. Medical coding is carried out by physicians (1½ full-time equivalent) and trained medical coding staff (10 full-time persons), supported by an academic staff and IT coordinator (1 full-time equivalent). Duplicate registrations are readily picked up with the help of the personal ID number. The entire coding process is supported by computer checks of consistency between variables (sex, codes, procedures, etc.), warning programmes and manual check procedures. New tumour cases are then included in the registry's computerised database and additions or corrections are made to previously notified cases. If the information received is incomplete or contradictory, an inquiry is made to the notifying clinician. All data up to 1977 were classified according to a modified version of ICD-7 expanded to include information on histology and tumour behaviour. All cases diagnosed since 1978 have been classified according to the ICD-O as well as the modified ICD-7.

Reported cases of cancer are linked to the Central Population Registry using the personal identification number, the identity is checked and information corresponding to the date of diagnosis is transferred to the registry file.

The entire registry database is cross-checked annually by computerised record linkage with all deaths that occur in the country. Medical certification of death by medical doctors is compulsory. Follow-back on death certified cancer cases unreported to the cancer registry is accomplished by mailed enquiries to the certifying physician or hospital. Less than 2% remain as death-certificate-only cases.

Computerised medical information systems on hospital discharges have been operating nationally since 1977. Since 1987, cases are also captured from this registry but only included if confirmed. In preparation for extensive computerised data capture from 2004, the reporting of cancer to the discharge registry was expanded and improved to fulfil the requirements of the cancer registry.

Interpretation and use of data

Assessments by linkage to patient discharge registers, pathology registers, and patient series have shown that the completeness of the registry is 95–97%.

The registry produces morbidity statistics in relation to variation over time, age and geographical location, and is used extensively for research. Since 1978, incidence data have been published for each year separately. From 1999 onwards the annual incidence publication can be obtained electronically from http://www.sst.dk (search term: cancer) at the level of ICD-7, and tabulated electronically from 1977, or from the NORDCAN database http://www.ancr.nu where annual data are available from 1972.

Source of population
A continuous count of the population is maintained. The mid–year point has been taken for each year.

Multiple primary rules used
IACR rules (2004) on CI5 IX period.

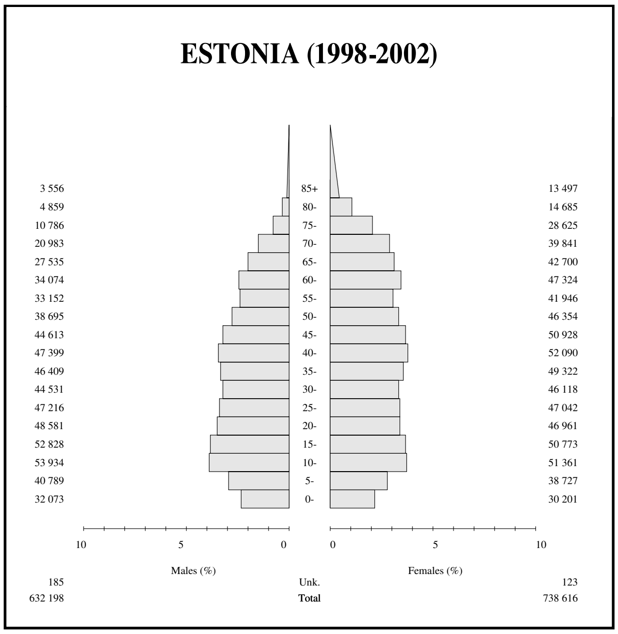
Estonia

Registration area

The Estonian Cancer Registry (ECR) covers the whole Republic of Estonia, population 1.4 million according to the 2000 census. Of the total population at the 2000 census, 68% were Estonians, 26% Russians, 2% Ukrainians, 1% Byelorussians and 3% other ethnic minorities; 69% of the population was living in urban areas. The life expectancy at birth was 65.1 years for men and 76.0 years for women.

Cancer care facilities

After Estonia regained independence in 1991, the national healthcare system was reorganised from a state-controlled system to a decentralised health-insurance-based system. Patients suspected of having cancer by the primary and secondary healthcare facilities are mostly referred to two specialised cancer hospitals, which provide radiotherapy, cancer surgery and chemotherapy. Some cancer treatment is performed in general hospitals (surgery) or other specialised hospitals/departments (neurosurgery, haematology, paediatric oncology).



Registry structure and methods

Cancer registration in Estonia dates to 1953 when compulsory registration of incident cancer cases started in the former USSR. The Estonian Cancer Registry was founded in 1978, while reliable incidence data are available since 1968. Until 1991, the Registry consisted of two subdivisions: (a) The Department of Statistics of the Estonian Cancer Centre (ECC), and (b) Department of Epidemiology and Biostatistics of the Institute of Experimental and Clinical Medicine. In 1991, the former of these subunits, responsible for the data collection, was renamed the Estonian Cancer Registry; the scientific analyses based on the Registry's data continued to be a responsibility of the latter subunit (since 2003, the Department of Epidemiology and Biostatistics of the National Institute for Health Development). The year 1994 was a landmark of major reorganisations in the Registry, particularly in the data collection procedures and the structure of the database. The Registry is funded from the state budget and employs a staff of five (Director, Data analyst, Physician-Data Manager, two Coding Clerks). Since the end of 2001, the ECR has operated as a subunit of the North-Estonian Regional Hospital Foundation's Cancer Centre.

Reporting of cancer cases in Estonia is compulsory. The Registry receives notifications from treating physicians and pathology and haematology laboratories. Coding and input are carried out in the Registry. The cancer patients are followed up to death or emigration. The data file for all death certificates issued in Estonia was provided annually by the Statistical Office of Estonia, and the Registry performed a trace-back procedure for cancer cases first notified by a death certificate. But due to the lack of legislative basis, the Registry has no access to death certificates issued in Estonia since 2001; therefore the incidence data may also be incomplete.

For updating the migration data and other personal data, in 2000 the Registry started regular linkage with the Population Registry (founded in 1992 when the national identification code was introduced in Estonia). In 1998, the data confidentiality issue was drastically emphasised in the public media. To solve the conflict between the Ministries and specify the legal aspects of personal data protection, the forwarding of notifications to the Registry was suspended for a month by administrative order. In February 2001, the Minister of Social Affairs issued a revised Decree (No. 21) on Cancer Registration and Running the Estonian Cancer Registry, providing access to the Registry's data in accordance with the Personal Data Protection Act. Recently, the Ministry of Social Affairs of Estonia has started to modify the existing laws in order to create the legal basis for all health registries, including the ECR.

The quality of the ECR's data has not been formally evaluated; the first study that partially covered this subject was carried out within the framework of a doctoral thesis by a young researcher and published in 2005.

Interpreting the results

No nationwide organised mass screening programmes for the early detection of cancer have been introduced in Estonia. However, the wide use of PSA testing since 1993 may have caused the rapid increase in detection of prostate cancer.

Opportunistic mammographic screening was introduced in some regions of the country in the 1990s and in the whole country in 2002. Also, an early detection project for cervical cancer in Estonia was introduced in 2003, and all regions were included by 2004.

Use of the data

The Registry publishes annual reports of cancer incidence, highlighting also time trends in incidence (the first report available for 1996, the last for 2000). Registry data have been used for a number of descriptive and analytical epidemiological studies, including international comparisons. In 1996, a statistical compendium, *Cancer in Estonia 1968–1992: Incidence, Mortality, Prevalence, Survival*, was published.

For the first time, the National Cancer Strategy was developed by the Working Group and presented to the Government in Spring 2000, but was not approved and financed. The present version of the Strategy covering the years 2007–2015, was submitted to the Government in 2006, and state funding will start in 2007.

Source of population
1998–1999: Estimate, based on 1989 census, making allowance for births, deaths and migration and revised after 2000 census. 2000: census. 2001–2002: estimate, based on 2000 census, making allowance for births and deaths but not for migration.

Multiple primary rules used
IACR rules (2004) on historical data.

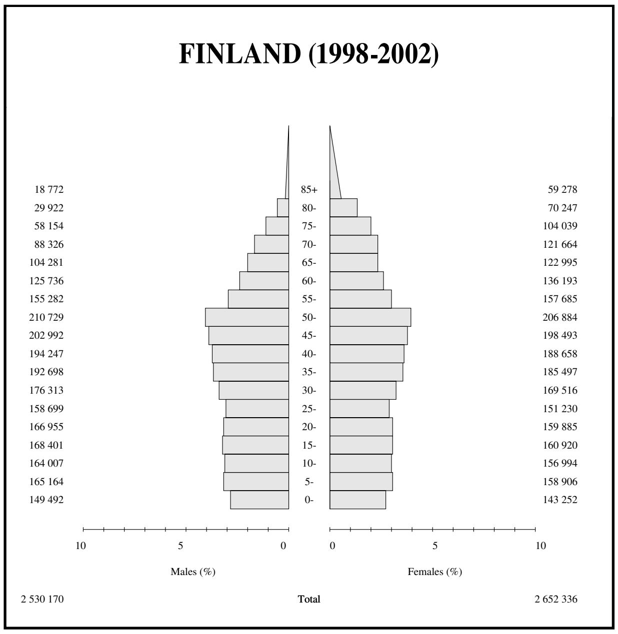
Finland

Registration area

The Registry covers the whole of Finland (area 338 145 km^2), which is bordered to the north by Norway, to the east by Russia, to the west by Sweden and the Gulf of Bothnia, and to the south by the Gulf of Finland. The average altitude is 150m. Finland has 33 615 km^2 of inland water and belongs to the coniferous forest zone. The population of Finland is 5 181 000 (2000). Ethnically, the Finns are Caucasian, and of mixed origin, including Baltic, Scandinavian and probably eastern elements; 85% are Lutherans. The official languages of the country are Finnish and Swedish; 5.6% of the population speak Swedish as their mother tongue. The main occupational groups are: industry (26.8%), services (65.5%) and agriculture and forestry (6.1%). Some 60% of the population lives in urban municipalities. The population of Helsinki with its suburbs accounts for 18% of the total. The life expectancy at birth is 73.7 years for males and 81.0 years for females.

Cancer care facilities

In 1999 Finland had 15 800 physicians (3 per 1000 inhabitants) and 39 700 hospital beds (excluding psychiatric hospitals). The country is divided into 22 healthcare districts, of which five (Helsinki, Turku, Oulu, Kuopio and Tampere) have a university teaching hospital. Diagnosis and treatment of cancer is only partly centralised; cancer surgery is practiced in all major hospitals and also in many smaller clinics. Nine hospitals have a radiotherapy unit. Specialised paediatric oncological services are available in five university hospitals.



FINLAND (1998-2002)

Registry structure and methods

The Finnish Cancer Registry (Institute for Statistical and Epidemiological Cancer Research) was established in 1952 on the initiative of the Cancer Society of Finland. Data on newly diagnosed cancer cases have been collected since 1953. Finland has been included in all the previous eight volumes of Cancer Incidence in Five Continents.

The total number of employees in the registry is 36, of whom 22 are at the cancer registry and 14 at the Mass Screening Registry (part of the Finnish Cancer Registry). There are 7 senior officials; IT personnel, secretaries and clerks account for 20 more, and researchers an additional nine.

The principal sources of information on cancer cases are physicians and hospitals, pathological laboratories and death certificates from Statistics Finland.

Reporting of cancer cases has been compulsory since 1961. If needed, requests are sent to notifiers in order to ensure accurate information of the identity of the individual in question, and primary site and date of diagnosis of the tumour. Coding of information at the Cancer Registry has always been done or supervised by a physician. Case identification is based on the personal identification number used in Finland since 1967. This also enables accurate follow-up of cancer patients for death through official sources. Besides continuous quality control procedures, formal evaluations also take place.

Nationwide screening programmes for breast, cervical and colorectal cancer are coordinated, monitored and evaluated by the Mass Screening Registry that is a part of the Cancer Registry. Opportunistic PSA testing is very common.

Use of the data

Apart from producing routine statistics (annual incidence rates by sex, age, primary site and healthcare district) and data for planning and health education purposes, the Registry is actively engaged in research on cancer epidemiology, biometrics and cancer patient survival, and provides material for clinical and pathological studies, and follow-up data on cancer patients. The Registry also acts as a consultant body in Finland on issues related to cancer epidemiology and research.

Source of population

A census count of the population is performed on a continuous basis by the Population Register Centre. The average annual population for 1998–2002 is published by Population Statistics, Statistics Finland.

Multiple primary rules used

IACR rules, modified by the cancer registry.

Notes on the data

C44 does not include basal cell carcinoma.

France, Bas-Rhin

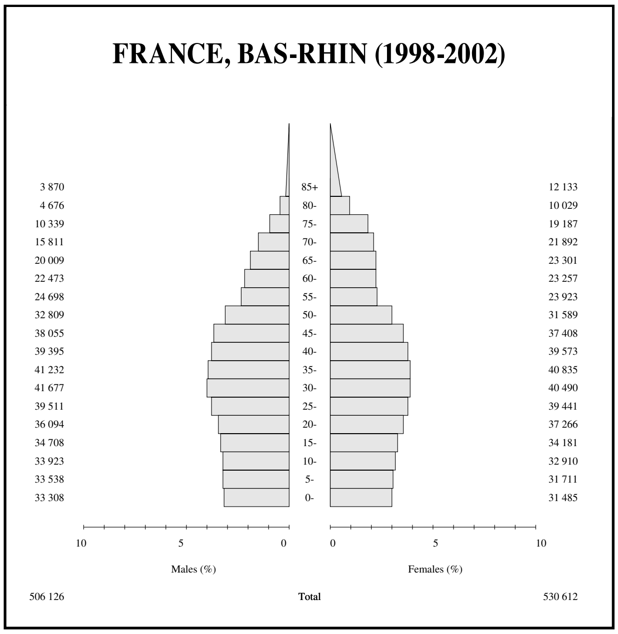
Registration area

The “département” (French administrative district) of Bas-Rhin constitutes the northern half of the Alsace region, occupying the west side of the plain drained by the Rhine, which represents a natural border with Germany. On the opposite side the Bas-Rhin reaches the massif of the Vosges on the west, with a total area of 4 58 km^2. The town of Strasbourg is its regional centre. Forest covers 30% of the land area. The maximum altitude (1100m) is reached in the Vosges, and the minimum (32m) on the Rhine plain. The climate is temperate to semi-continental.

The population consisted of 1 026 120 inhabitants in 1999 (density: 216 inhabitants/km^2). Of these, 54.4% live in an urban environment in agglomerations with over 5000 inhabitants, and 27.6% in villages with fewer than 2000; 40.8% live in the urban district of Strasbourg. The population is slightly younger than the general French population.

The economically active population amounts to 53.1% of the total population: 67.0% of these work in the services sector, 30.8% in industry, and 2.2% in agriculture.

The département is without mineral resources and does not produce any raw materials, but has a major energy-production industry (petrol refineries and hydroelectric stations). The mechanical and electrical construction industry and the food industry (including breweries and wine production) are the most important. Agriculture plays an important role in spite of the low percentage of the population employed in this sector.



Bas-Rhin is a relatively wealthy département: incomes are high, and the level of consumption is also high, notably for food. Life expectancy in 1999 was 75 years for males and 82 years for females.

Cancer care facilities

Bas-Rhin has a high level of medico-social equipment, with 8457 hospital beds in 1999 (1 bed per 121 inhabitants), 1636 general practitioners and 1802 specialists. Hospitals employ 37.2% of all doctors. Many scattered small rural hospitals allow for hospital care close to the place of residence. More than 70% of cancer patients die in hospitals.

Registry structure and methods

The activity of the Cancer Registry of Bas-Rhin began in 1974. The registration of cases covers the resident population of the département of the Bas-Rhin.

Cancer registration is active, the doctors from the registry visiting each of many sources regularly to establish lists of new cases and to complete an epidemiological questionnaire. The lists from each of these sources are compared to ensure complete registration and to eliminate errors, particularly duplicate registrations. Cancers discovered by autopsy are registered. Death certificates are not used as a source, but serve only to verify the completeness of registration.

For each case of cancer registered, the identity and address of the patient are noted as well as the date of diagnosis, the method of diagnosis, the pathology department, the identification number of the pathological examination, the topography and morphology coded to ICD-O, and the behaviour. The two sources where the most complete information was found are also noted, as well as the identification number of the medical file, the date of death or the date of last information concerning vital status of the patient.

The identity of the patients is used only to avoid registering more than once the same patient with the same cancer. The data are coded by the doctors who have visited the information sources.

Lesions or cancers diagnosed or discovered *in situ* and with histological verification are registered, but are not included in calculations of incidence.

Interpreting the data

Organised breast cancer screening of the population aged 50–65 has been carried out since 1989 (20 000 examinations annually). Organised screening for cervical cancer was introduced in 1994 for women aged 25–65. Screening for cancer of other sites is opportunistic.

Source of population

INSEE: http://www.insee.fr

Multiple primary rules used

IACR rules (2004) on historical data.

Notes on the data

C44 not available.

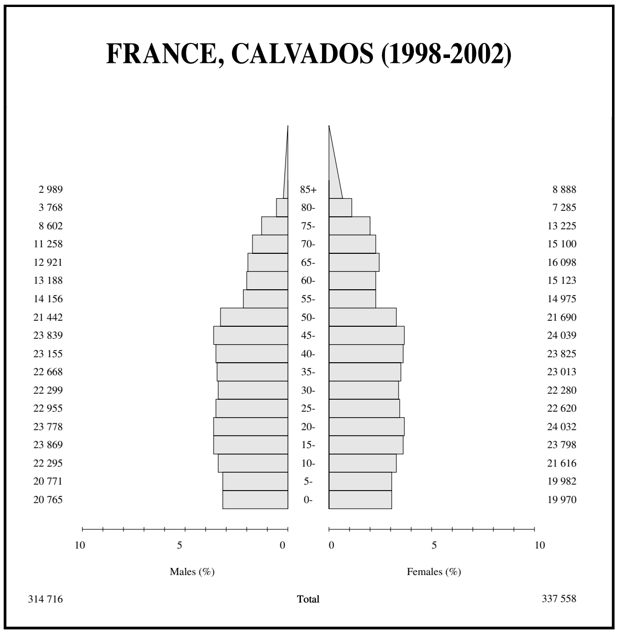
France, Calvados

Registration area

The *département* (French administrative district) of Calvados covers an area of 5548 km^2. Situated in Normandy, it includes parts of the Armorican Massif (Bocage) and the Paris Basin (Pays d'Auge, Plaine de Caen, Bessin). To the North is the coastline of the English Channel. The highest elevation is 365m above sea level. The dèpartement of Calvados includes 621 rural communes (37.7% of the population) and 84 urban communes. There are 652 273 inhabitants, of whom 6.9% are aged 75 years and older. Among those employed (250 725 individuals), 5.2% are in agriculture, 19% in industry, 5.6% in building, 13.6% in commerce, and 56.6% in the service industries. In 1999, unemployment was 7.4%.

Registry structure and methods

Two cancer registries, both located in Caen, the departmental capital, cover the dèpartement of Calvados. The general registry is located at the Comprehensive Cancer Centre François Baclesse, and the specialised digestive tumour registry at the University Hospital. These two registries are supported by the National Institute for Heath and Medical Research (INSERM) and by the Health Watch Institute (InVS) of the Ministry of Health. They also receive contributions from the Conseil Régional de Basse-Normandie. They are affiliated with the French Association of Cancer Registries (FRANCIM), and to the EUROCARE network.


FRANCE, CALVADOS (1998-2002)

Registration has been carried out without interruption since 1978, using data from private as well as public medical facilities. They include a University Hospital, one regional comprehensive cancer centre and one cancer hospital, 22 general hospitals, 2160 doctors including 1137 specialists, and five pathology laboratories.

Registration is active, and information is directly taken from the medical and pathology records. Death certificates are also referred to; however, cases for which information only originates in death certificates are not registered.

Completeness is ensured by linking the information collected from all sources. The index date is the date of first pathological diagnosis or, if not available, the date of first diagnosis (radiological or biological). TNM stage and treatment are routinely coded for digestive tumours. Follow-up information is collected at regular intervals from treating doctors as well as from public registry offices for all cases. Data from the different registries are linked periodically in order to exclude cases registered twice. Paper documentation is kept for each case.

Use of the data

In addition to analysis of incidence and trends, many studies are conducted: change of disease stage at diagnosis, evaluation of mass screening, evaluation of treatment impact on survival, and survival trends. Relationships between environmental factors and oesophageal cancer, colorectal cancer, peritoneal and pleural mesotheliomas are also studied, as well as occupational exposure to pesticides and cancer.

Source of population

INSEE: http://www.insee.fr.

Multiple primary rules used

IACR rules (2004) on historical data.

Notes on the data

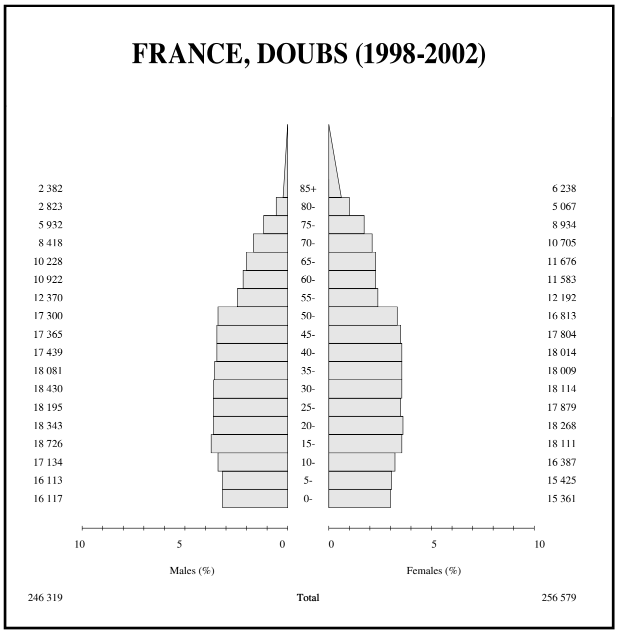
C44 not available.

France, Doubs

Registration area

The registration area is the Doubs *departement* (French administrative district), which covers 5234 km^2. According to the 1999 census, the total population comprises 499 062 inhabitants, of whom 346 720 live in urban areas and 152 342 in rural areas. The economically active sector includes 204 219 residents, and the unemployment rate is 10.4%. A notable proportion of residents living by the border cross it to work in Switzerland. There are 26 262 foreigners who work in the department, mostly from North Africa. The main religion is Roman Catholic.

There are two industrial areas: one in Sochaux-Montbeliard, with a large automobile factory, and the other in Besançon, the main city, which has several small industries that produce little or no pollution.



Cancer care facilities

There was one physician per 523 inhabitants in 1999. The entire population is covered by health insurance. Nearly all Doubs residents are treated in the departement. There are two oncology-radiotherapy wards, one in the teaching hospital of Besançon and one in the general hospital of Montbéliard. During the study period there was no cancer screening programme (the breast screening programme began in 2003).

Registry structure and methods

The Doubs Cancer registry began its activities in 1976. The registry is mainly supported by the InVS (Institut de Veille Sanitaire, a national agency funded by the Health Ministry, and by the teaching hospital of Besançon.

The registry uses active and passive casefinding from 38 sources of data consisting of public and private pathology laboratories, computerised hospital and clinic discharge recording systems, and medical records. The law allows physicians to transmit data to registries. In the registration area, there are only a few physicians who do not collaborate with the registry. The few residents treated outside of registration area are found using discharge recording systems of hospitals and clinics outside the registration area. Death registration is based on death notification in the patient's birthplace. The registry staff visits the sources and consults computerised medical records to collect data.

Data collection follows rules and recommendations of the ENCR. All types of invasive tumours are included (basal and squamous cell skin cancer are included) as well as uncertain-behaviour tumours and *in situ* tumours of the urinary bladder, and *in situ* tumours of the cervix and breast. Benign tumours of the brain and *in situ* tumours of colon and rectum and melanoma were not included for the study period but have been registered since 2003. French registries must maintain data security, confidentiality and information to patient following recommendations of the CNIL (Commission Nationale Informatique et Liberté), and the Doubs registry has developed internal checking and rules to follow these recommendations. Checking for duplicates is done at data entry, and regularly verified on the database using computer programmes.

Uses of the data

The registry prepares an annual report of cancer incidence, highlighting trends and changes. It collaborates with the French Cancer Network FRANCIM to publish studies on national and regional incidence estimates as well as survival and evaluation of care studies. The registry also conducts specific studies in collaboration with local clinicians and epidemiologists.

Source of population

INSEE: http://www.insee.fr.

Multiple primary rules used

IACR rules (2004) on historical data.

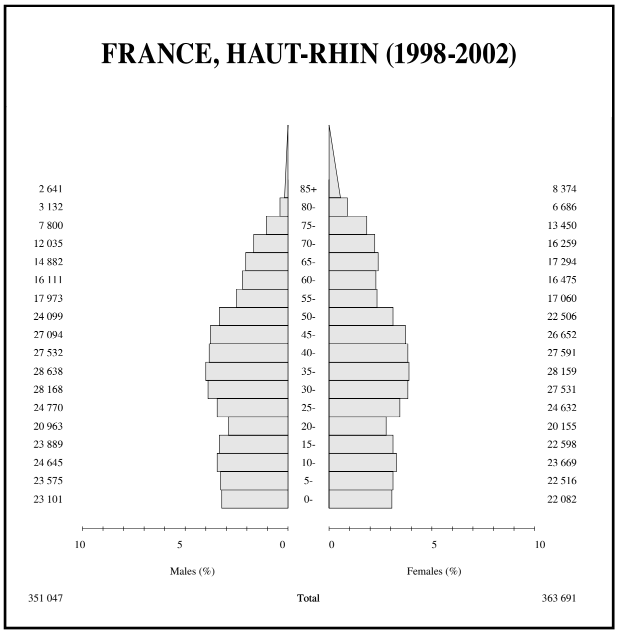
Notes on the data

C44 not available.

France, Haut-Rhin

Registration area

The *département* (French administrative district) of Haut-Rhin, an area of 3522 km^2, is situated in the northeast of France. It is adjacent to the département of Bas-Rhin in the north (with which it constitutes the Alsace region), the département of the Vosges to the west, and the Franche-Comté region and Switzerland to the south. To the east, the Rhine separates Haut-Rhin from Germany. The altitude varies from 195m on the Rhine to 1424 m in the Vosges mountains. The climate is semi-continental, with fairly cold winters and hot, dry summers. The conditions favour the vineyards of the lower slopes of the Vosges. The area has four geographical regions: the Vosges mountains (crystalline massif), the lower hills of the Vosges (wine and fruit cultivation), the plain of the Rhine (land of loess and former marshland), and the Alsacian Jura (limestone).



The population of Haut-Rhin is divided into 377 communes, of which 269 are rural with fewer than 1000 inhabitants. Haut-Rhin has a higher proportion (47%) of economically active (aged 15–64) persons and a lower proportion aged over 65 years than France as a whole. Foreigners make up 8.1% of residents, of whom 69% were born outside metropolitan France. The population is 21% rural; 52% live in the 23 communes with more than 5000 inhabitants. The urban area of Mulhouse has 228 115 inhabitants. The average population density is 201 inhabitants per km^2, varying from 81 in the rural communes to 4975 in the commune of Mulhouse.

The unemployment rate is 9% among men and women. The industrial sector employs 25% of the active population (automobile, arms, chemicals, textiles, wood and paper, nuclear power); the agricultural sector 2% (market gardening, wine production, forestry), the building sector 6%, and the tertiary sector 67% (commerce, administration, education, health, transport). A special feature related to the geographical situation of Haut-Rhin is that 12% of the employed population resident in the département works in Switzerland or Germany.

Cancer care facilities

With 98 general practitioners and 63 specialists per 100 000 inhabitants, the medical coverage of the Haut-Rhin population is below the national French average (respectively 113 and 88). The hospital infrastructure, public and private, comprises 1582 beds in medical wards, 1141 in surgery, and 325 in gynaecology and obstetrics. There are two radiotherapy wards, one in the south (Mulhouse), and the other in the north (Colmar). There is no specialised cancer centre in the département.

Registry structure and methods

The Haut-Rhin Cancer Registry is a general population-based registry. Created in 1989, it is administered by an association under a specially constituted law for the purpose. It is entirely financed by local funds (local and regional groups, health insurance funds, the Anti-Cancer League).

The registry collects information on all new cases of cancer occurring among the inhabitants of Haut-Rhin, including those diagnosed and treated elsewhere. Registration is active. The main sources of information are pathology and cytology laboratories, and radiotherapy, oncology, paediatrics and haematology services. The medical information departments and medical records departments of the hospitals are also excellent sources of first notifications. Cases discovered at autopsy are registered, and identified as such. The data collected are systematically verified, completed or modified, using secondary sources (hospitalisation services, treating physicians). The average number of sources per registered case is over three. Death certificates are not used.

Data are entered using the IARC CanReg software.

Use of the data

The registry was established in order to obtain data on the burden of cancers in the area, so as to maintain an updated database for evaluation of public health measures in the prevention, screening and treatment of cancer.

Source of population

INSEE: http://www.insee.fr.

Multiple primary rules used

IACR rules (2004) on historical data.

Notes on the data

C44 not available.

France, Hérault

Registration area

The registry is located in Montpellier, the capital of the Hérault *département* (French administrative district), which is part of the Languedoc-Roussillon region and covers 6101 km^2 in the south of France, near the Mediterranean.

In 2000 the population of Hérault comprised 920 000 inhabitants (48% males, 52% females) with a population density of 151 inhabitants per km^2. The departement is highly urbanised (the urban population is 4.25 times the rural population).

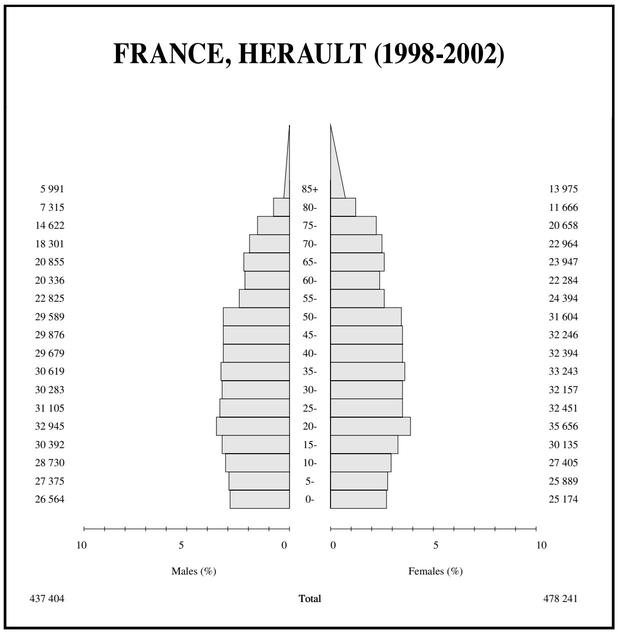
Of the active population, 81.1% work in the services sector, 15% in industry and 3.9% in the agricultural sector. The unemployment rate is 14.5%.

The population is slightly older than the general French population (23.1% older than 60, vs. 19.8% in France). Life expectancy is 76.3 years for males and 83.2 years for females (vs. 75.9 and 82.9 years in France, respectively).

The birth rate is 12.0 per 1000 and the mortality rate 9.5 per 1000 (vs. 12.7 and 9.0 per 1000 respectively in France).

Cancer care facilities

Hérault has a high level of medico-social equipment, with 2.5 beds per 1000 inhabitants in medicine and 2.2 beds per 1000 inhabitants in surgery (vs. 2.2 and 1.8 per 1000 inhabitants in France respectively) distributed among one hospital specialising in cancer, 10 public hospitals (including one academic hospital in Montpellier and 6 small rural hospitals) and 16 private clinics. The medical coverage of the Hérault population is greater than the national average of 200 general practitioners and 246 specialists per 100 000 inhabitants.



FRANCE, HERAULT (1998-2002)

Registry structure and methods

The majority of the registry's budget comes from the National Health Department through InVS (Institut de Veille Sanitaire) but also from INSERM (Institut National de la Santé et de la Recherche Médicale) and Hérault Committee's League against Cancer.

The registry staff consists of five persons: one medical epidemiologist, one secretary, two registrars and one investigator.

Our principal sources of information on cancer cases are 11 pathological laboratories, one hospital specialising in cancer, 3 radiotherapy units, 2 general hospitals, 10 private clinics, general and specialist practitioners, and the medical files of 2 health insurance companies. For data collection, 20% are collected via active search, 65% by passive notification, and 15% as pre-coded data from the hospital specialising in cancer. Registration is active: medical and pathology records are consulted directly by medical doctors and registry investigators.

The administrative information is coded by the registrars and all medical information is coded by the medical director of the registry. Death certificates are not used as a source.

All invasive and *in situ* cancers are registered, with the exception of basal cell carcinomas of the skin. Stages are registered for all localisations and coded according to the TNM 5th edition.

There is active follow-up of the registered cancer cases since 1997.

Interpreting the results

Since 1990, we have had two organised breast cancer screening programmes for women aged 40–49 years and 50–69 years. Hérault is the only French area covered by a cancer registry in which there is an organised breast screening programme for women aged 40–49 years.

Use of the data

A report of all data is published biannually. The last report was published in April 2005 for cancers diagnosed in 2001–2002. All incidence data, chronological tendencies and relative survival by sex, age and stages for each organ are detailed. Screening programmes for breast cancer are evaluated.

The Hérault Cancer Registry performs many studies (case–control studies, medical economic studies, evaluation of therapeutic practices), alone and in collaboration with other French or European registries.

Source of population

INSEE: http://www.insee.fr.

Multiple primary rules used

IACR rules (2004) on historical data.

Notes on the data

C44 not available.

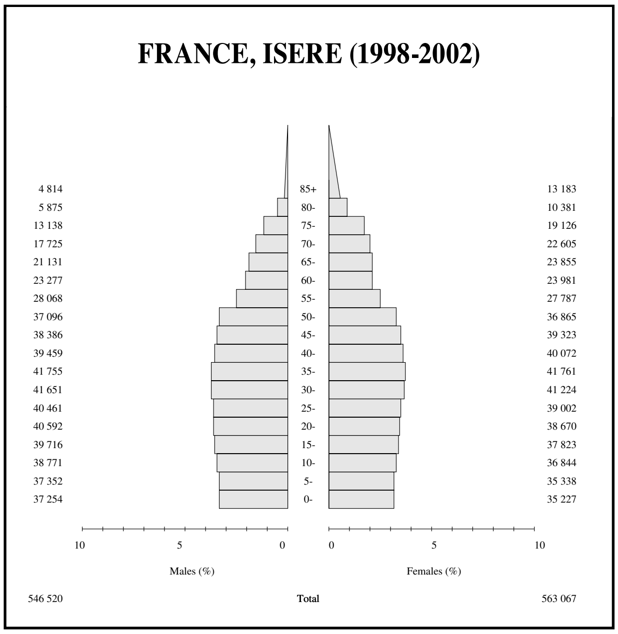
France, Isère

Registration area

The Isère Cancer Registry covers the population of the *département* (administrative region) of Isère in southeastern France. Besides some recreational activities (e.g. ski resorts, lakes), industrial activities are important (chemical production), and research and teaching (universities). Less than 20% of the population resides in rural areas. In 2002 the population was estimated to be 1 126 000, with 301 000 people under age 20, 622 000 aged 20–59 years and 203 000 over age 60.

Cancer care facilities

In 2001, the density of specialised and general practitioners was 206 per 100 000 inhabitants. In December 1999, there were 3586 physicians in charge of the population's health in Isère. There are two specialist cancer hospitals, and diagnosis and treatment are also undertaken in general hospitals and private clinics.



Registry structure and methods

Of the registry's budget, 70% comes from the Isère General Council (Conseil Général) and from InVS (Institut de la Veille Sanitaire) and INSERM (Institut National de la Santé et de la Recherche Médicale). The bulk of the research work is funded by the French League against Cancer and by foundations or by contracts with industrial companies. The registry staff, both for registration and research work, consists of two clerks (part-time), two registrars (part-time), 1.6 medical epidemiologists, one statistician and one secretary. For some studies, extra medical interviewers are hired.

Among the sources of information, in Isère and in three contiguous areas, there are 34 laboratories providing pathological reports. The registry also obtains information from two hospitals specialising in cancer, 13 general hospitals, the network of hospitals in the city of Lyon, six private clinics and the medical files of two Health Insurance Companies. Since 1997, abstracts of the medical files from the hospital patient-disease information systems are received for most patients treated for cancer, at least for hospitals in the public domain. All of the information received is carefully checked and when judged insufficient, registry staff visit the sources where they scrutinise the records kept in the medical records departments. As death certificates are anonymous, they are of no use for case-finding. There is no active follow-up of the registered cases, except for specific survival studies.

Interpreting the results

An active screening programme (breast, colon and cervix) and well-implemented habits of PSA testing for prostate cancer may explain rather high incidence rates for these tumours, as compared with French standards. In operation since 1985 (PSA) and 1990 (screening), these activities probably no longer have an effect on trends, but some research has shown an increase in the proportion of localised compared to distant tumours, which supports a beneficial effect of those programmes for the population's health.

Systematic sending of medical record abstracts by hospitals may improve coverage in coming years.

Use of the data

A report for researchers and people in charge of cancer in Isère is published annually. The prevalence of cancer has been estimated. Mapping of disease is carried out by the registry. The screening programmes for breast, colon and cervix cancers are evaluated.

The registry also undertakes surveillance of occupational cohorts. In co-operation with other French Cancer Registries (FRANCIM) and the Institut de la Veille Sanitaire, the registry contributes to the detection of new cancer risks in the French population.

Analyses of different methods of diagnosis and treatment for some cancer sites, including breast, prostate, bladder, kidney and colon cancer, have been carried out as well.

Source of population

INSEE: http://www.insee.fr.

Multiple primary rules used

IACR rules (2004) on historical data.

Notes on the data

C44 not available.

France, Loire-Atlantique and Vendée

Registration area

The registration area is composed of the two *départements* (French administrative districts) of Loire-Atlantique and Vendée, situated in western France, which cover 13 535 km² and have a total population of 1 134 493 for Loire-Atlantique and 539 806 for Vendée according to the 1999 census. The population density figures were 172 and 84 inhabitants per km² in Loire-Altantique and in Vendée respectively. About 54% of the Loire-Atlantique population and 25% of the Vendée population live in urban areas (≥10 000 inhabitants).

Cancer care facilities

There are 23 public and 37 private hospitals in the two départements, including one university hospital and two anticancer centres. Most radiotherapy and chemotherapy structures are present in the 3 main towns (Nantes, Saint Nazaire, La Roche-sur-Yon). The two départements have 2613 general practitioners and 2520 specialists (respectively, 108 and 62 per 100 000 inhabitants).

Registry structure and methods

The Loire-Atlantique and Vendée Cancer Registry is a general population-based registry. Created in 1998, it is one of the biggest French Registry, affiliated with the association of French Cancer Registries (FRANCIM) and recognized by the National Committee of Registries (CNR). It is administered by an association according to the French association law of 1901. It is entirely financed by the General Council, the Regional Council, the Departmental League Against Cancer, the Loire-Atlantique private anticancer centre, the National Institute for Medical Research (INSERM) and the Health Watch Institute (InVS).

The registry is located within the university hospital of Loire-Atlantique (CHU Nantes) and the departmental public hospital of Vendée (CHD La Roche-sur-Yon). The registry is staffed by a medical epidemiologist, a part-time anatomopathologist and 10.5 full-time equivalent persons.

Cancer cases are found by an active search in the medical records from several sources of data. The three main sources are pathologists, medical information systems in the hospitals and clinics, and health insurance notifications. The registry staff visits these sources, where they scrutinise the records kept in medical records departments, to identify and abstract information on cases of cancer (diagnosis and treatment of cancers) among residents of the registry départements. Until now, death certificates have been forbidden by law to be used as data sources for registries in France.

Although cancer is not a notifiable disease, a few registration forms are received from private practitioners. Arrangements have been made with the hospitals outside the registration area to notify the registry of any resident cancer cases that they diagnose and treat.

Quality in the registry is monitored every four years by the National Committee of Registries (CNR). The Registry is monitored by the National Commission of Data Processing and Freedom (CNIL) for confidentiality.

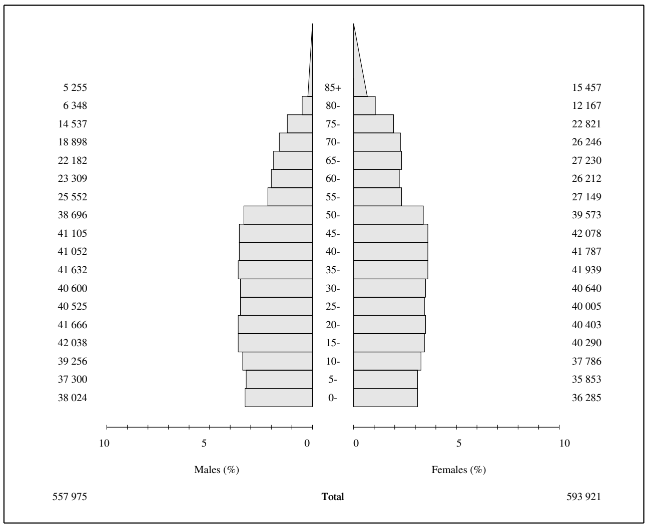
Interpreting the results

Organised breast cancer screening of the population aged 50-74 has been carried out since 1996 in Loire-Atlantique and since 2002 in Vendée.

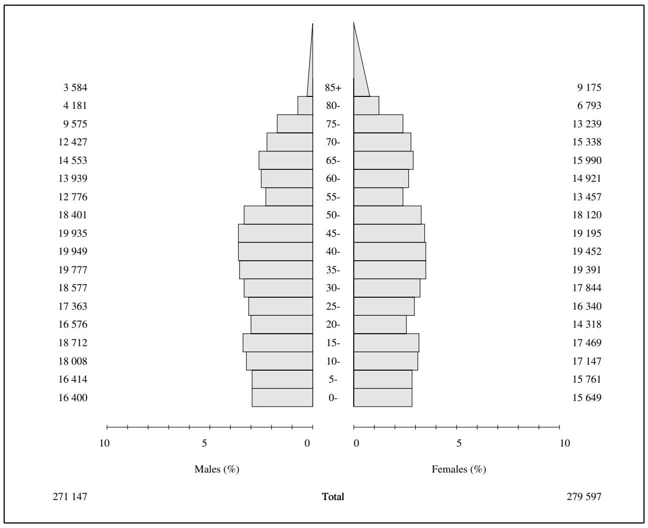
Uses of the data

The Loire-Atlantique and Vendée Cancer Registry has produced basic descriptive data and participated in collaborative studies at a national level. It prepares an annual report of cancer incidence, highlighting trends and changes. Some special studies have been carried out (including evaluation of clinical care for breast cancer or colon cancer, and survival).

FRANCE, LOIRE-ATLANTIQUE (1998-2002)



FRANCE, VENDEE (1998-2002)



Source of population

INSEE: http://www.insee.fr.

Multiple primary rules used

IACR rules (2004) on historical data.

Notes on the data

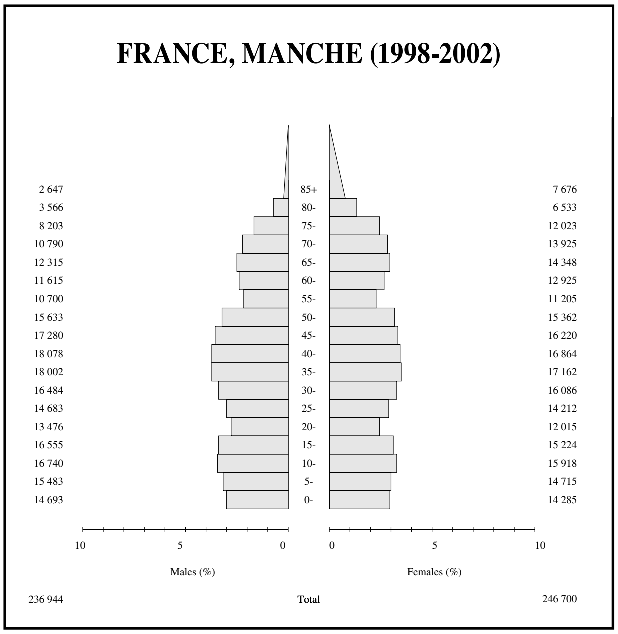
C44 not available.

France, Manche

Registration area

Situates in the area of Basse Normandie, the *département* (French administrative region) of the Manche covers 5938 km^2 and has 330km of coastline. It is a part of the Armorican massif and consists of three different zones: in the north the Cotentin peninsula; in the centre a formerly swampy zone, now meadows; in the south the hills of the Norman bocage, which reach 368m. The climate is of the oceanic type. The department contains 602 communes, 86% of which have fewer than 1000 inhabitants. The population is slightly older than the national average. It is mainly rural, with only 48% living in the five urban areas (of which half are in the only urban zone, Cherbourg, in the North) and density is low (81 habitants per km^2).

The working population represents 43.2% of the total population. Among those employed, 47.5% are in the service sector, 19.9% in industry (predominantly farm produce), 14.4% in agriculture, 10.4% in commerce and 7.8% in building and public works. In 1999 the unemployment rate was 11.5%. The département has a low proportion of foreigners (0.8%). The economy is mainly agricultural, breeding representing 90% of this production. Fishing and tourism are developed in the coastal zones. There is an industrial area in the north, mainly the nuclear industry (nuclear waste reprocessing plant, surface storage facility for nuclear waste, power station) and shipyards.



FRANCE, MANCHE (1998-2002)

Cancer care facilities

With 611 general practitioners and 511 specialists in 2002, the department has a low medical coverage. There are seven beds per 1000 inhabitants. The department possesses 11 public hospitals, general and local, and seven private care structures. There is no specialised cancer centre, but there are two radiotherapy units, one private in the south of the department, one public in the north which is a delocalised structure associated with the regional cancer care centre of the neighbouring department (Calvados).

Registry structure and methods

The Cancer Registry of Manche began its activities in 1994. The registry is based in Cherbourg, in the general hospital, and was created by an association of practitioners of the department. It is supported by the Ministry of Health, the Regional Council of Basse Normandie, the General Council of Manche, the local League against Cancer, communes, local associations, and industries. It is affiliated with the association of French Cancer Registries (FRANCIM).

Data collection is active in Manche and the surrounding departments. The registration of cases covers the resident population of the department of the Manche. The sources of information are regional, including 12 pathology and cytology laboratories, services of oncology, radiotherapy, paediatrics and haematology, and medical records departments of hospitals. After first notification of cases, every medical file is checked in regional, private and public, medical facilities, and then coded to ICD-O by the physician. All invasive and *in situ* cancers are registered except basal cell skin cancers. Death certificates are not used as a source of data. The registry carries out active follow-up of all cases from the municipal registry office.

The industrial characteristics of the north of the department led to the implementation of a specialised collection system for haematopoietic cancers. It consists of collection of reports from the medical biology laboratories of the department, validation by a haematologist, and records of immunophenotypic, conventional cytogenetic and molecular data, and the tumour cells are cryopreserved.

Use of the data

The Manche Cancer Registry produces basic descriptive data and participates in collaborative studies at a national and international level.

Source of population

INSEE: http://www.insee.fr.

Multiple primary rules used

IACR rules (2004) on historical data.

Notes on the data

C44 not available.

France, Somme

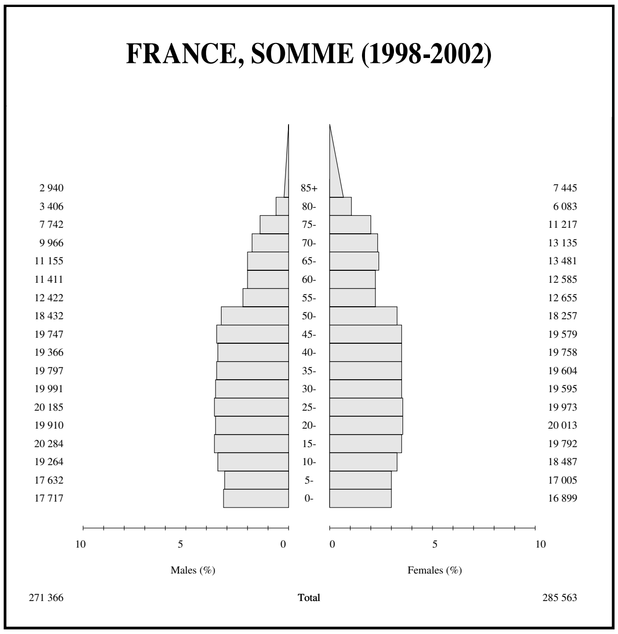
Registration area

Situated 140km from Paris, the Somme registry covers 6170 km^2, includes 60km of coastline and is composed of three main types of landscapes: Bocage in the West, Picardy plateau at the centre, and Santerre in the East, occupied by extensive cultures. The river Somme passes through and is bordered by ponds and marshes attracting many anglers and hunters. Tourism is developed. The Bay of Somme is a natural reserve and a landing zone for migratory birds.

The population is 41.5% rural. The West of the county is traditionally both rural and industrial, with factories producing taps and locks. There is also a large industrial area around Amiens.

The Somme Registry is the only general registry north of Paris. The population census in 2000 counted 557 121 inhabitants. Amiens is the principal town with 136 000 inhabitants; the other towns count less than 30 000 inhabitants.

The natural population increase by birthrate is +2.6% (INSEE 2003).



Cancer care facilities

There's no specialised cancer care centre in the département. Cancer care is shared by the University Regional Hospital and the general hospitals and clinics located in six towns of Somme. Ten percent of patients are treated outside the registration area in cancer care centres in Paris or Lille (to the north), or in a general hospital or clinic in Saint-Quentin and Chauny (Aisne département). Chemotherapy and radiotherapy are dispensed privately or publicly. Since about 1998 physicians groups have organised multidisciplinary examinations of patient records to improve quality of treatment and more consistently apply national consensus standards of care.

Since 1997 the regional health authority has recognised cancer as one of the priorities of the county. The registry is acknowledged to be the best tool to monitor cancer in the community.

Registry structure and methods

Somme cancer registry is managed by the "1901 law" and funded by Institut de Veille Sanitaire, Inserm, County committee of National League against Cancer and General Council. It forms part of FRANCIM network.

The registry is presided over by a Public Health Professor and counselled by another Public Health Professor; there are also an epidemiologist doctor (DM, PhD), a technical director (MSc), two inquirers/registrars and a secretary.

Cancer cases are collected by active search from listings and in medical records of about 90 sources of data. The two main sources are pathologists and medical information offices of public and private hospitals, but also registers of chemotherapy and radiotherapy in two clinics, The Regional Factory Inspectorate, Parisian hospitals administration, and regional cancer centres contribute to collection. Every year the registrars contact the outside sources and consult their records.

Cancer is not a notifiable disease in France. Identifying data are known only by registry staff. The Registry refers its work to "Commission Nationale Informatique et Libertés". Every four years the registry undergoes a quality audit by Registries National Committee.

Interpreting the results

A written agreement was signed with private pathologists and a public one in 1998, so the incidence has increased since then. There have been no changes in case definition and coding.

A screening programme for breast cancer has existed since 1990. In 1996 PSA testing was introduced, and we have likewise improved monitoring of prostate cancers.

There are no known unusual environmental, occupational exposures that may influence incidence.

Melanomas and squamous cell carcinomas of skin are not likely to be exhaustive, for many are diagnosed by non-corresponding pathologists in Paris.

Use of the data

Tables of incidence are carried out every year, and trends are produced for physicians on request. Area oncologists also receive the results of any specific studies.

Somme is a participating registry in the Eurocare project, Europreval and European Rare Cancers studies, Epilymph, and Eurodeucatam.

The Somme registry has been part of the Regional Schedule of Care organization since 1994, and a member of the Oncopic network.

Source of population

INSEE: http://www.insee.fr

Multiple primary rules used

IACR rules (2004) on historical data

Notes on the data

C44 not available.

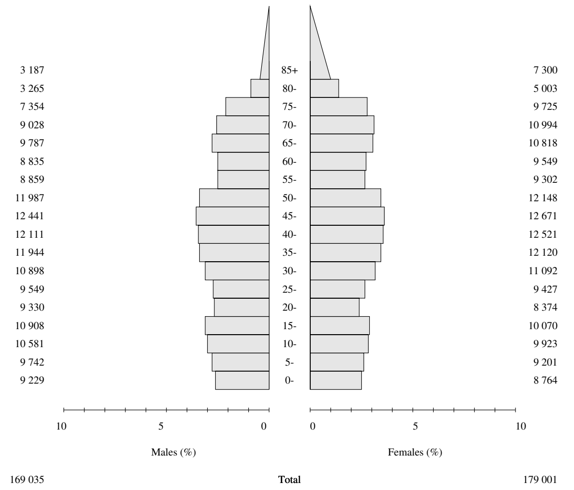
France, Tarn

Registration area

The department of Tarn is part of the Midi-Pyrenean region, situated in the southwest of France. It covers an area of 5758 km^2, mostly situated south of latitude 44°N and on longitude 2°E. In 1999, the population was composed of 343 402 inhabitants, with an urban/rural ratio of 1.65, and a ratio of French citizens to foreigners of 22.8. The population overall is slowly increasing (344 620 at mid-year 2000), but certain areas are undergoing quite a rapid increase while others are in recession.

The Tarn Cancer Registry was created in 1981. The arguments favouring the creation of a Registry in this department included the insufficient development of population-based cancer registries in France at this time and their absence in the Southwest, and certain characteristics of the department of Tarn such as the age-structure of its population and its relative stability with little migration, the large size of its rural population and some longstanding industries such as tanning, textiles and minerals.

FRANCE, TARN (1998-2002)



Cancer care facilities

The department of Tarn is fairly autonomous in its provision of cancer care facilities. These are complemented by a cancer care network. Medical coverage is high, with 118 general practitioners and 118 specialists per 100 000 inhabitants, including four pathologists, two medical oncologists and two radiotherapists. There are four public hospitals and four private clinics in the department of Tarn. However, a few types of cancer (haematological, paediatric) are sent to the specialised services of the University Hospital or to the Regional Cancer Control Centre, both situated in Toulouse, the capital of the region.

In the department of Tarn, a programme of organised breast cancer screening has existed since 2003, and a colorectal cancer screening programme is underway. However these elements do not affect the data published here, given that the period of study is 1998-2002.

Registry structure and methods

The Tarn Cancer Registry operates as a French Law 1901 Association and is constituted by representatives of the medical and university sectors, and of the elected officials of the department and the Midi-Pyrenean region. Funding for registration activities comes from the General Council of Tarn, the departmental committee of the National League Against Cancer and the Ministry of Health. Research is funded through grants.

The staff, composed of 11 people (8.8 full-time equivalents) carries out both registration activities and research.

The search for the cases is active, and four investigators of the registry staff visit the data sources. The different laboratory, private and public hospital departments, administrative services and medical specialists in Tarn are regularly visited, with a frequency varying according to caseload in the different sources. The staff also visit Toulouse University Hospital and the Regional Cancer Control Centre. In recent years, the search for cases in public hospitals has been simplified by the existence of Medical Information Departments, which provide computerised lists of the cancer cases treated in those establishments. Name-specific death certificates are not used as a source of information, according to French law.

For each case, a notification form is completed with the medical and administrative information from the medical file. The names of the doctors involved in the diagnosis and the treatment of the patient, including primary physician, are systematically noted in order to contact them if necessary.

When the forms arrive in the registry, the secretaries first check the computing database to avoid duplicate registrations. The cases are then systematically checked in a second source by the investigators. If information is not sufficient, a questionnaire is sent to the regular doctor. These procedures allow missing information to be completed and patients with metastasis from or recurrence of a cancer diagnosed prior to 1982, or not resident in the area, to be excluded.

The medical information on the remaining cases is coded by the Medical Director of the registry, assisted by specially trained coders. The administrative data are coded by two secretaries. The data are then entered onto the computer of the registry, creating a computing file which can be updated when additional information from other sources reaches the registry. This file has been declared to the National Commission on Information and Liberty (CNIL).

Active follow-up by writing to the town halls where the patients were born and writing to the regular doctor is only carried out for cases that are the object of special studies.

Use of the data

In addition to basic descriptive epidemiology, the Tarn Cancer Registry carries out several studies, alone or in collaboration with other registries (the Association of French Cancer Registries FRANCIM and the European Network). These include estimates of the incidence and prevalence of cancer in France, the study of time trends, case–control studies and evaluation of diagnostic and therapeutic regimes for selected sites.

Source of population

INSEE: http://www.insee.fr.

Multiple primary rules used

IACR rules (2004) on historical data.

Notes on the data

C44 not available.

Germany, Federal States of Berlin, Brandenburg, Mecklenburg-Western Pomerania, Saxony-Anhalt and the Free States of Saxony and Thuringia

Registration area

The Common Cancer Registry (CCR) covers the population of the federal states Berlin, Brandenburg, Mecklenburg-Western Pomerania, Saxony-Anhalt and of the Free States of Saxony and Thuringia, all located in the east part of Germany and constituting the territory of the former German Democratic Republic (GDR), except for West Berlin. Thus, the CCR is the only cancer registry in Germany that covers several states. The population in the catchment area of the CCR is about 17.1 million inhabitants, 48.9% males and 51.1% females (2002), almost all of them being of Caucasian origin. About 59% live in urban areas (defined as population >5000 and population density >400 inhabitants per km^2).

Cancer care facilities

The territory covered by the CCR has 339 hospitals (Berlin 71, Brandenburg 47, Mecklenburg-Western Pomerania 34, Saxony-Anhalt 51, Saxony 86, Thuringia 50), most of them affiliated with a regional tumour centre. Although there are some hospitals specialising in oncology services, most of the other hospitals are involved in cancer care as well (e.g. offering special diagnostic or treatment methods). The tumour centres, however, are the focal point in cancer care. Tumour centres are specific hospitals and university hospitals specialising in diagnostics, treatment, and aftercare of cancer patients and the documentation of pertinent information. Also, general practitioners, radiotherapy departments and other specialists are involved in cancer care on an outpatient basis.

Registry structure and methods

The CCR is located in Berlin and is associated with the Senate Department for Health, the Environment and Consumer Protection (Senatsverwaltung für Gesundheit, Umwelt und Verbraucherschutz) in Berlin. The registry is funded by the contributing states according to their population size and is staffed with 1 physician, 3 mathematicians/statisticians/computer experts, 2 epidemiologists, 15 documentation or coding employees and 2 administration secretaries.

In Germany, cancer is a reportable disease. Cancer notification became mandatory in all states of the CCR (Saxony 1993, Mecklenburg-Western Pomerania 1998, Saxony-Anhalt 2000, Thuringia 2003, Berlin 2004, Brandenburg 2006). Patients are informed about the notification to the registry by the diagnosing physician.

The major sources of notification in the CCR are the regionally organised tumour centres (Tumorzentren). Tumour centres cooperate with the population-based registry in that they abstract all pertinent information from medical records of cancer cases seen in a hospital or special clinic affiliated with a tumour centre and report them to the CCR. There are about 30 tumour centres reporting to the CCR, providing >90% of all notifications per year. The remaining 10% the registry receives directly from the physician via the traditional reporting by means of notification forms. Additionally, all death certificates have been made available to the registry by local health authorities. Data of German non-residents of the CCR are exchanged with neighbouring cancer registries.

The cancer registration law from 1995 requires, for reasons of confidentiality, that all population-based registries have two independent units (in terms of space, organisation and personnel): one unit handling incoming (person identifying) notification (“Vertrauensstelle”) and one unit holding the epidemiological data set and conducting the statistical analysis with the anonymised data (“Registerstelle”).

Registration and quality control are performed according to the ENCR and IACR guidelines. Accuracy of the information is checked in an automated manner, in that implausible or questionable information will be identified and corrected if necessary. Annually, our data are formally evaluated on completeness by the Robert-Koch-Institute, the National Cancer Reporting Unit.

Interpreting the results

After 1989 the notification rate declined sharply due to political changes in the former GDR and the resulting lack of a legal framework for cancer registration. With the cancer registration law taking effect in 1995, the legal basis was re-established for the CCR and cancer cases were again reported to the registry. The availability of death certificates as a principal source of information on cancer cases was regulated by the cancer registration law. Since 1995, the number of reported cancer cases has steadily increased, while the percentage of DCO cases is decreasing. Note that although cancer is a reportable disease, it became mandatory only recently for some of the states of the CCR (see above).

There are opportunistic screening programmes for colorectal, prostate, cervical and female breast cancer and for skin melanoma. Data on testing for PSA are not available, but it is increasing in this population.

In the past there were some unusual occupational exposures of radon for employees in the Wismut mining area (West Saxony and East Thuringia), as well as unusual environmental exposures of radon in houses which might still be a problem in parts of this area today.

Use of the data

CCR data have been used for health services planning and for epidemiological research. Linkage with the CCR was performed for case–control and cohort studies. Annual reports on cancer incidence and mortality are published for the entire population of the CCR. In addition, state-specific reports are prepared on request. In cooperation with the association of population based cancer registries in Germany (GEKID) and the Robert-Koch-Institute, the data are pooled for nation-wide analyses.

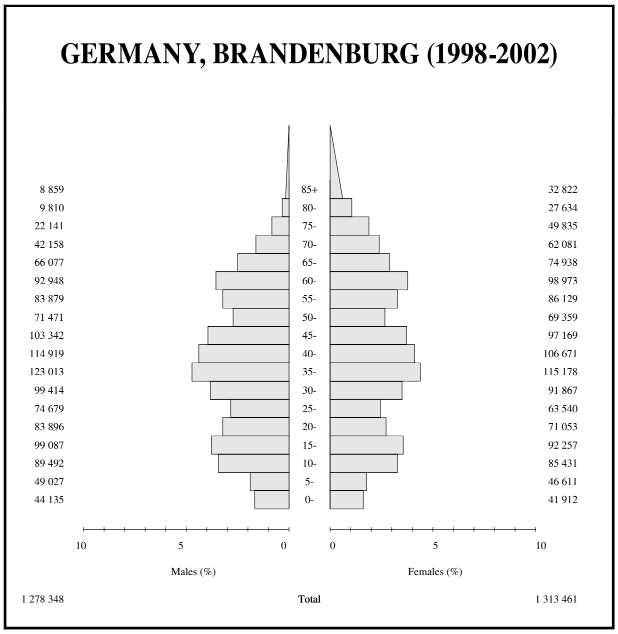
Germany, Brandenburg

Registration area

The state of Brandenburg is one of the six states covered by the Common Cancer Registry (CCR) and is located in the North-East of Germany. The population of Brandenburg is about 2.6 million inhabitants, 49.4% males and 50.6% females (2002), almost all of them being of Caucasian origin. About 48% live in urban areas (defined as population >5000 and population density >400 inhabitants per km^2).

Cancer care facilities

In Brandenburg there are 47 hospitals, most of them affiliated with one of the regional tumour centres (see below). The state of Brandenburg has five tumour centres, located in the cities of Cottbus, Frankfurt/Oder, Neuruppin, Potsdam and Schwedt. Although there are some hospitals specialising in oncology services, most of the other hospitals are involved in cancer care as well (e.g. by offering special diagnostic or treatment methods). The tumour centres, however, are the focal point in cancer care. Tumour centres are specific hospitals and university hospitals specialising in diagnostics, treatment, and aftercare of cancer patients and the documentation of pertinent information. Also, general practitioners, radiotherapy departments and other specialists are involved in cancer care as they see cancer patients in an outpatient setting.


GERMANY, BRANDENBURG (1998-2002)

Registry structure and methods

For a description of the structure of the registry, please refer to the general narrative for the CCR.

In Brandenburg, cancer is a reportable disease. However, cancer notification became mandatory only recently (2006). Patients are informed about the notification to the registry by the diagnosing physician.

The major sources of notification in Brandenburg are the regionally organised tumour centres (Tumorzentren). The tumour centres abstract all pertinent information from medical records of cancer cases residing in the state of Brandenburg seen in a hospital or special clinic affiliated with a tumour centre and report them to the CCR. The tumour centres provide 99% of all notifications per year. Thus, the registry receives only 1% of the notifications directly from the physician via traditional reporting by means of notification forms. Additionally, all death certificates have been made available to the registry by local health authorities. Data on German non-residents of the CCR are exchanged with neighbouring cancer registries.

Interpreting the results

After 1989 the notification rate in Brandenburg declined sharply due to political changes in the former GDR and the resulting lack of a legal framework for cancer registration. With the cancer registration law taking effect in 1995, the legal basis for cancer registration was re-established and cancer cases were again reported to the registry. The availability of death certificates as a principal source of information on cancer cases was regulated by the cancer registration law. Since 1995, reported cancer cases from Brandenburg have been steadily increasing, while the percentage of DCO cases is decreasing. Note that although cancer is a reportable disease, it became mandatory only recently for the state of Brandenburg (see above).

There are opportunistic screening programmes for colorectal, prostate, cervical and female breast cancer and for skin melanoma. Data on testing for PSA are not available, but it is increasing in this population.

We are aware of no unusual environmental and/or occupational exposures in Brandenburg.

Use of the data

Brandenburg cancer data have been used for health services planning and for epidemiological research. Linkage with the CCR was performed for case-control and cohort studies. Annual reports on cancer incidence and mortality are prepared. In cooperation with the association of population based cancer registries in Germany (GEKID) and the Robert-Koch-Institute, the data are pooled for nation-wide analyses.

Source of population

The estimate of the population at risk is based on an extract from the central residents' registration office on 3 October 1990, which is annually updated with the results of the statistics of births, deaths and migration. Source: Statistisches Amt der Länder.

Multiple primary rules used

IACR rules (2004) on CI5 IX period

Germany, Mecklenburg-Western Pomerania

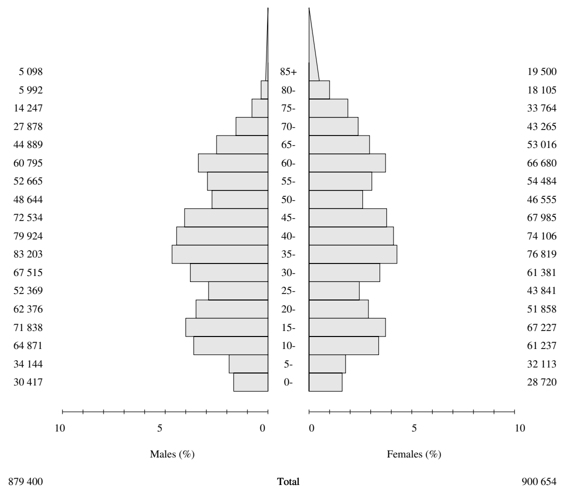
Registration area

The state of Mecklenburg-Western Pomerania is one of the six states covered by the Common Cancer Registry (CCR) and is located in the North-East of Germany. The population of Mecklenburg-Western Pomerania is about 1.8 million inhabitants, 49.5% males and 50.5% females (2002), almost all of them being of Caucasian origin. About 36% live in urban areas (defined as population >5000 and population density >400 inhabitants per km^2).

Cancer care facilities

In Mecklenburg-Western Pomerania there are 34 hospitals, most of them affiliated with one of the regional tumour centres (see below). The state of Mecklenburg-Western Pomerania has four tumour centres, located in the cities of Greifswald, Neubrandenburg, Rostock and Schwerin. Although there are some hospitals specialising in oncology services, most of the other hospitals are involved in cancer care as well (e.g. by offering special diagnostic or treatment methods). The tumour centres, however, provide a focal point in cancer care. Tumour centres are specific hospitals and university hospitals specialising in diagnostics, treatment, and aftercare of cancer patients and the documentation of pertinent information. Also, general practitioners, radiotherapy departments and other specialists are involved in cancer care, as they see cancer patients in an outpatient setting.

GERMANY, MECKLENBURG-WESTERN POMERANIA (1998-2002)



Registry structure and methods

For a description of the structure of the registry, please refer to the general narrative for the CCR.

In Mecklenburg-Western Pomerania, cancer is a reportable disease. In 1998, cancer notification became mandatory in this state. Patients are informed about the notification to the registry by the diagnosing physician.

The major sources of notification in Mecklenburg-Western Pomerania are the regionally organised tumour centres (Tumorzentren). The tumour centres abstract all pertinent information from medical records of cancer cases residing in the state of Mecklenburg-Western Pomerania seen in a hospital or special clinic being affiliated with a tumour centre, and report them to the CCR. The tumour centres provide 95% of all notifications per year. The remaining 5% the registry receives directly from the physician via the traditional way of reporting by means of notification forms. Additionally, all death certificates have been made available to the registry by local health authorities. Data of non-residents of the CCR are exchanged with German neighbour cancer registries.

Interpreting the results

After 1989 the notification rate in Mecklenburg-Western Pomerania declined sharply due to political changes in the former GDR and the resulting lack of a legal framework for cancer registration. With the cancer registration law taking effect in 1995, the legal basis for cancer registration was re-established and cancer cases were again reported to the registry. The availability of death certificates as a principal source of information on cancer cases was regulated by the cancer registration law. Since 1995, the number of reported cancer cases from Mecklenburg-Western Pomerania has been steadily increasing, while the percentage of DCO cases is decreasing.

There are opportunistic screening programmes for colorectal, prostate, cervical and female breast cancer and skin melanoma. Data on testing for PSA are not available but it is increasing in this population.

We are not aware of any unusual environmental and/or occupational exposures in Mecklenburg-Western Pomerania.

Use of the data

Mecklenburg-Western Pomerania cancer data have been used for health services planning and for epidemiological research. Linkage with the CCR was performed for case-control and cohort studies. Annual reports on cancer incidence and mortality are prepared. In cooperation with the association of population based cancer registries in Germany (GEKID) and the Robert-Koch-Institute, the data are pooled for nation-wide analyses.

Source of population

The estimate of the population at risk is based on an extract from the central residents' registration office on 3 October 1990, which is annually updated with the results of the statistics of births, deaths and migration. Source: Statistisches Amt der Länder.

Multiple primary rules used

IACR rules (2004) on CI5 IX period.

Germany, Free State of Saxony

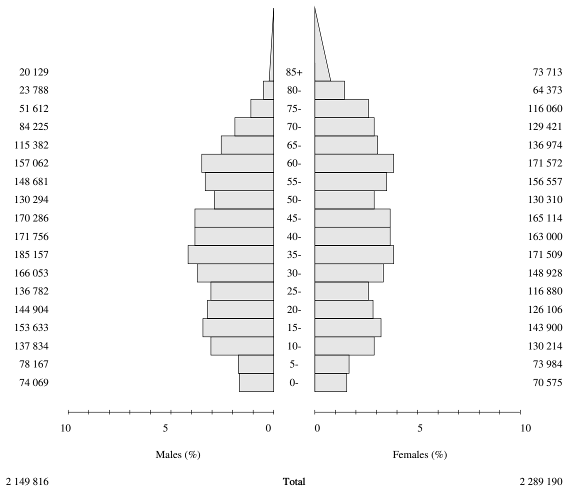
Registration area

The state of Saxony is one of the six states covered by the Common Cancer Registry (CCR) and is located in the East of Germany. The population of Saxony is about 4.4 million inhabitants, 48.5% males and 51.5% females (2002), almost all of them being of Caucasian origin. About 57% live in urban areas (defined as population >5000 and population density >400 inhabitants per km^2).

Cancer care facilities

In Saxony there are 86 hospitals, most of them affiliated with one of the regional tumour centres. The state of Saxony has five tumour centres, located in the cities of Chemnitz, Dresden, Görlitz, Leipzig, and Zwickau. Although there are some hospitals specialising in oncology services, most of the other hospitals are involved in cancer care as well (e.g. by offering special diagnostic or treatment methods). The tumour centres, however, are the focal point in cancer care. Tumour centres are specific hospitals and university hospitals specialising in diagnostics, treatment and aftercare of cancer patients and the documentation of pertinent information. Also, general practitioners, radiotherapy departments and other specialists are involved in cancer care, as they see cancer patients in an outpatient setting.

GERMANY, FREE STATE OF SAXONY (1998-2002)



Registry structure and methods

For a description of the structure of the registry, please refer to the general narrative for the CCR.

In Saxony, cancer is a reportable disease. In 1993, cancer notification became mandatory in this state. Patients are informed about the notification to the registry by the diagnosing physician.

The major sources of notification in Saxony are the regionally organised tumour centres (Tumorzentren). The tumour centres abstract all pertinent information from medical records of cancer cases residing in the state of Saxony seen in a hospital or special clinic affiliated with a tumour centre and report them to the CCR. The tumour centres provide 93% of all notifications per year. The remaining 7% the registry receives directly from the physician via the traditional reporting by means of notification forms. Additionally, all death certificates have been made available to the registry by local health authorities. Data of German non-residents of the CCR are exchanged with neighbouring cancer registries.

Interpreting the results

After 1989 the notification rate in Saxony declined sharply due to political changes in the former GDR and the resulting lack of a legal framework for cancer registration. With the cancer registration law taking effect in 1995, the legal basis for cancer registration was re-established and cancer cases were again reported to the registry. The availability of death certificates as a principal source of information on cancer cases was regulated by the cancer registration law. Since 1995, the number of reported cancer cases from Saxony has been steadily increasing, while the percentage of DCO cases is decreasing.

There are opportunistic screening programmes for colorectal, prostate, cervical and female breast cancer and for skin melanoma. Data on testing for PSA are not available, but it is increasing in this population.

In the past there were some unusual occupational exposures of radon for employees in the Wismut mining area (West Saxony), as well as unusual environmental exposures of radon in houses which might be still a problem in parts of this area today.

Use of the data

Saxony cancer data have been used for health services planning and for epidemiological research. Linkage with the CCR was performed for case–control and cohort studies. Annual reports on cancer incidence and mortality are prepared. In cooperation with the association of population based cancer registries in Germany (GEKID) and the Robert-Koch-Institute, the data are pooled for nation-wide analyses.

Source of population

The estimate of the population–at–risk is based on an extract from the central residents' registration office on 3 october 1990 which is annually updated with the results of the statistics of births, deaths and migration. Source: Statistisches Amt der Länder.

Multiple primary rules used

IACR rules (2004) on CI5 IX period

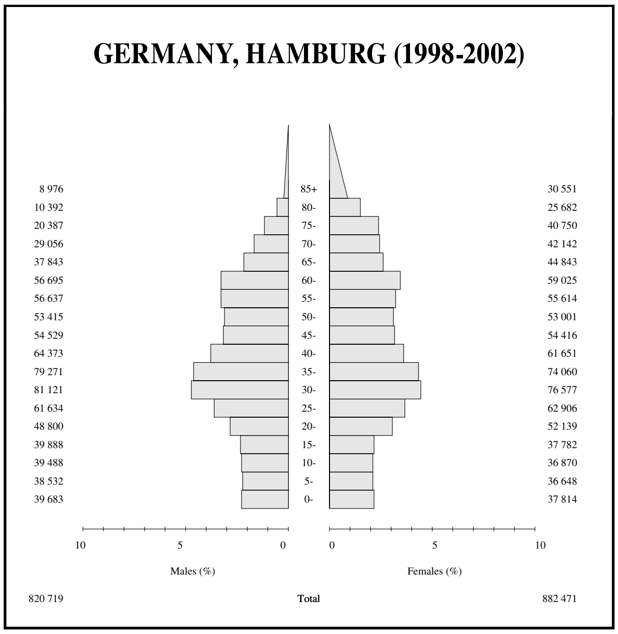
Germany, Hamburg

Registration area

With 1.7 million inhabitants, the Free and Hanseatic City of Hamburg is the second-largest city in Germany and one of the 16 federal states. The city area comprises 755 km^2, 14% of which are covered by green spaces, water and recreational areas. Hamburg is one of the world's major trade centres. Its port is the central hub for trade with Eastern and Northern Europe, supplemented by important rail and motorway connections. The predominantly urban area shows highly specialised industries, particularly medical devices, biotechnology and aircraft industry. With 11 universities, higher education is a main focus.

Cancer care facilities

Being a metropolitan area, the medical infrastructure in the city of Hamburg is above-average. Medical care is provided by a complex healthcare system including 3600 general practitioners and specialists, and 53 hospitals including a university hospital. The main institutions of specialised cancer care are about 10 hospital departments and 8 oncological practices, the latter including in- and outpatient settings. These are supplemented by numerous diagnostic, therapeutic and supporting facilities, such as laboratories, pathology units, radiology and radiotherapy institutions and psycho-social services. Up to 25% of oncological patients reside outside of Hamburg.



Registry structure and methods

Having started between 1926 and 1929, the Hamburg Cancer Registry (HCR) is one of the oldest population-based cancer registries of the world. During the Second World War the reporting process stopped, and again paused in the 1980s because of a general controversy on data protection in Germany. Since 1985 the HCR has been based on a specific law with two essential elements: the principle of informed consent from the patient and voluntary cooperation on the physician's side. Since 1991 notifications are remunerated.

The state health authority, staffed with four scientists, two computer experts and six documentation and coding employees, runs the HCR. Additional project equipment is provided by the Hamburg cancer society.

Traditionally the physicians in hospitals report by means of notification forms. Pathologists provide a partly filled notification form to be completed by the attending physician. Electronic data transmission is now realised by providing purpose-developed software to the cooperating practitioners. This software transfers data from the surgery's software into an electronic notification form completed on screen by the physician. A rising number of hospitals are supplied with facilities to enable electronic notifications as well.

In addition, all death-certificates are made available to the cancer registry staff for evaluation and trace back. The procedure of matching the HCR-data with information kept in residential registry offices was started in 2004. The step was a one-time check of 75 000 cases without date of death. Since then the update has been done monthly. Many plausibility tests are done, and a "Best-of tumour information" is generated in case of multiple notifications of a single malignancy.

Interpreting the results

Since 1995 the number of notifications to the HCR has doubled while the DCO rate has declined significantly. Completeness is independently reviewed by the Robert Koch Institute based on the M/I index, having been estimated in 2005 as sufficiently complete. Nevertheless quality differs considerably concerning site and year of diagnosis.

Although methods of early detection are used widely (e.g. Pap smear, PSA, mammography) it is impossible to quantify their numbers and to estimate their influence on incidence rates.

Use of the data

Comprehensive reports on cancer incidence and mortality in Hamburg are published every third year. In addition, in 2004 the HCR started publishing data online (www.krebsregister.hamburg.de). Routine reports cover data on incidence and mortality. In 2005 we began including survival analysis for clinical use.

In cooperation with the Association of population-based cancer registries in Germany (GEKID) and the Robert-Koch-Institute (RKI) the data are pooled and documented in *Krebs in Deutschland*.

The HCR both initiates and participates in various research projects, for instance risk factors for breast carcinoma, regional analysis of incidence concerning leukaemia and lymphoma, feedback on long-term survival to notifying institutions, acute and post-traumatic stress disorder in breast cancer patients.

One current project is the multi-centre MARIE- Study (Postmenopausal Hormone Replacement Therapy and breast cancer risk). The HCR also collaborates with the hospital planning unit of the Ministry of Health in Hamburg in the assessment of numbers of cancer cases given from the hospitals, and is involved in the evaluation of mammography screening.

Source of population

Projection (Statistical office for Hamburg and Schleswig–Holstein, http://www.statistik–nord.de).

Multiple primary rules used

IACR rules (2004) on CI5 IX period.

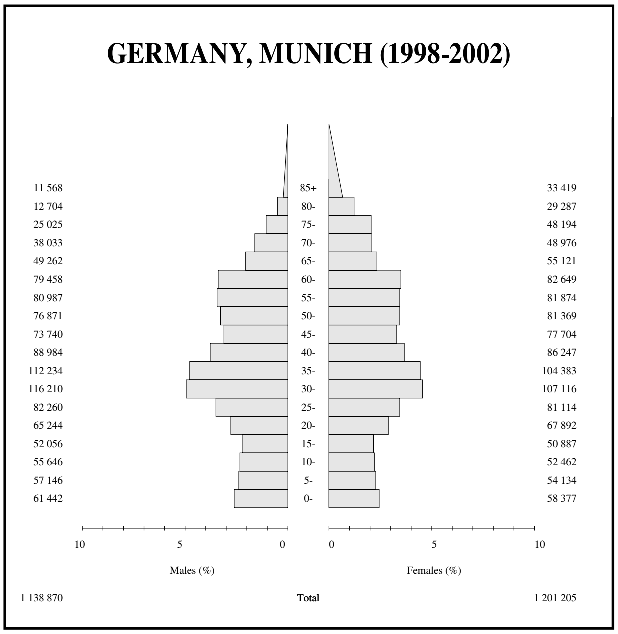
Germany, Munich

Registration area

Munich is the capital of the federal state of Bavaria, one of sixteen states of the Federal Republic of Germany (Munich City: latitude 48°8' N, longitude 11°34' E, 519m above sea level, area 310km^2). With its 1.3 million inhabitants, Munich is Germany's third-largest city, located in the southeast of the country about 50km north of the Alps.

The Munich Cancer Registry (MCR) covers the population of the City of Munich and 7 surrounding districts, in total 2.3m inhabitants, 56% living in Munich City. About 23% of the inhabitants are foreigners, 8.6% from the EU. Most of them come from Turkey (3.4%), and from Croatia, Serbia, Greece, Austria and Italy each with about 1.7%. Most work in the service and trade sector and in growth industries such as media, information and communication technology, the financial industry and biotechnology. Munich is Germany's second-largest university city.

In 1998, legislation was passed authorising population-based cancer registration in Bavaria. The registration system in Bavaria for a total of 12.4m people, based at the Munich Cancer Centre and five other comprehensive cancer centres, has been centralised to further improve the collection and processing of cancer data. Since 2007 the MCR has covered the entirety of Southern Bavaria, with 4.4m inhabitants.



GERMANY, MUNICH (1998-2002)

Cancer care facilities

Hospitals and private practitioners provide health care in the region. There are two university hospitals in the city of Munich. All necessary diagnostic and treatment services are available to deliver healthcare according to international standards. The population-based stage distributions and treatment results show international comparability. All hospitals cooperate in the comprehensive Munich Cancer Centre.

The MCR supports networking in oncology by compiling cancer data from all sources. Presentation of individual and aggregated data is offered to the closed community of cooperating doctors.

Registry structure and methods

As part of the comprehensive Munich Cancer Centre, the MCR started registering patients in 1978. In the first years a few departments of the Ludwig-Maximilians-University and the Technical University Munich collaborated. There are now 39 hospitals in Munich, and 11 hospitals from the surrounding districts taking part in the MCR. The number of cooperating institutions and the catchment rate has reached a steady state and guarantees a high coverage rate.

Notification is on a voluntary basis, and no legal duty is imposed upon doctors to report cancer cases. Hospitals send cancer-specific forms with pre-coded data on an individual level, including identifying items for each primary malignancy. Additionally, collaborating hospitals report on local and regional progressions and on the occurrence of metastases. These data are important outcome criteria for clinicians and are used for evaluating therapeutic strategies and for quality control.

Since 1994, the 12 pathological services have been sending copies of the reports for malignant diagnoses to the MCR. The histological verification rate for almost all prognostic favourable types of cancer is 95%.

The Bavarian Cancer Registration Law allows the MCR to process all death certificates in the catchment area. Information from death certificates has been compared with registry data on an individual level since 1998. This has revealed a noteworthy underreporting for prognostically unfavourable cancer sites like pancreas, liver, gallbladder, CNS and lung. Remarkably, the age-standardised mortality rate for lung cancer in Munich is about 30% lower than the overall rate for Germany, corresponding to a high social status and low rate of smoking.

Haematological diseases are underreported. For the other cancer sites, a remarkable incidence rate could be obtained without involvement of DCO-cases and without including follow-back results. The impact on success of motivation to join the MCR can be assessed by analysing the stable incidence rate from 342.5/266.4 in 1998 to 361.7/ 271.0 in 2002 (male/female, world standard, without 174/C44).

In 2002 we handled about 29 000 pathological reports, 36 000 death certificates and 50 000 other forms and reports. Additionally, life status was verified by more than 100 000 requests at Resident's Registration Offices. This paperwork is done by 13 documentation officers. In addition three scientists are responsible for organisation, statistics and computer technology.

In Germany, cancer screening is offered but the participation rate varies widely between men and women, according to their age. Medical examination includes palpation of breast, cervical smear, haemoccult test and palpation of prostate, with a high rate of self-initiated PSA tests at the patients' own expense.

Use of the data

The MCR analyses cancer incidence and mortality concerning secular and regional aspects. Survival rates are calculated for the different cancer sites. Results are used to answer important questions, e.g. concerning quality assurance in health care. Additionally, the MCR releases periodical reports via Internet for all cooperating hospitals to keep them permanently informed about the medical data they have provided.

Many of the most frequent cancer diagnoses are analysed in detail. Routine statistics show comparisons to the recommendations of guidelines with hints to those patients for whom the standards are not realised. The larger hospitals are informed about their own results, main outcome criteria are compared anonymously with the other hospitals. Some of the data are available for the scientific community on the internet (www.tumorregister-muenchen.de).

Source of population
2000. Postcensal estimate.

Multiple primary rules used
IACR rules (2004) on CI5 IX period.

Germany, North Rhine-Westphalia: Münster

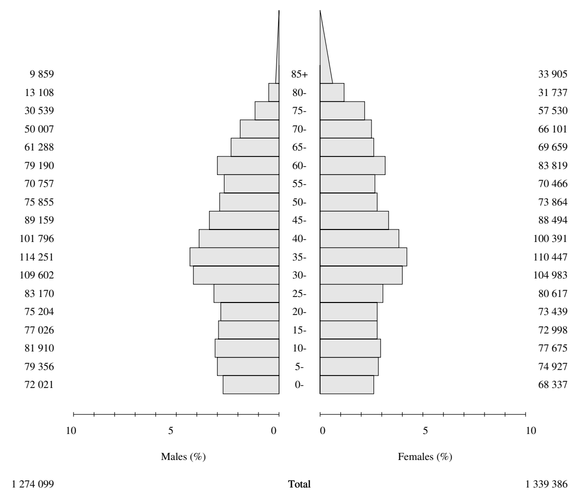
Registration area

The Muenster District (Regierungsbezirk) is a region of the Federal State of North Rhine-Westphalia (NRW). It is located in the north-west of Germany bordering the Netherlands. The population of Regierungsbezirk Muenster was 2 625 637 in 2002, with 48.8% males and 51.2% females and a population density of 379 inhabitants per km^2. The District encompasses rural areas as well as large industrial areas and cities. The great majority of the population are Caucasians. The Muenster Registry was the only cancer registry in NRW until 2005, when it was transferred into the Epidemiologisches Krebsregister Nordrhein-Westfalen, a new epidemiological cancer registry now covering the entire state of North Rhine-Westphalia.

Cancer care facilities

Cancer diagnosis and treatment in Regierungsbezirk Muenster are carried out by hospitals and specialists. There are 63 hospitals with more than 20 000 beds in the registration area. Morphological examinations and diagnoses are performed in 14 pathological institutes, one specialising in neuropathology and five in dermatohistology. Radiology services are provided by departments in numerous hospitals.

GERMANY, NORTHRHINE-WESTPHALIA: MUNSTER (1998-2002)



Registry structure and methods

The registry was established in 1985 and was completely funded by the State Ministry of Health. Full-time personnel comprise two senior scientists for data management and analysis, one epidemiologist, and four medical records clerks. A consultant from the Institute of Epidemiology and Social Medicine of the University of Muenster accompanies the registry.

Cancer notification requires the signed consent of patients. The sources of notification for the Muenster registry include hospitals, outpatient departments and private practitioners. Since 1998 the registry has included reports from pathologists with anonymised personal identifiers. Follow-up of patients is largely passive. Annually, the register database is linked with death certificates from the district. Follow-back is pursued if patients were initially identified in the register by death certificate.

Interpreting the results

The catchment area has remained unchanged over the reporting period. Likewise, the diagnostic and therapeutic facilities developed in line with the general medical progress in Germany. Coding has been performed according to ICD-10 and the ICD-O-3 guidelines throughout the period. No organised population-wide cancer screening programmes have been established, although opportunistic mammography, colonoscopy, skin inspection and PSA testing are rather common.

Use of the data

The registry prepares regular annual reports of cancer incidence and mortality. More detailed reports of trends and survival are prepared infrequently for specific entities (e.g. breast, leukaemia, malignant melanoma and prostate cancer). Data are also provided by an interactive database via Internet. The registry contributes frequently to the official Health Report System in North Rhine-Westphalia.

Source of population

Census.

Multiple primary rules used

IACR rules (2004) on CI5 IX period.

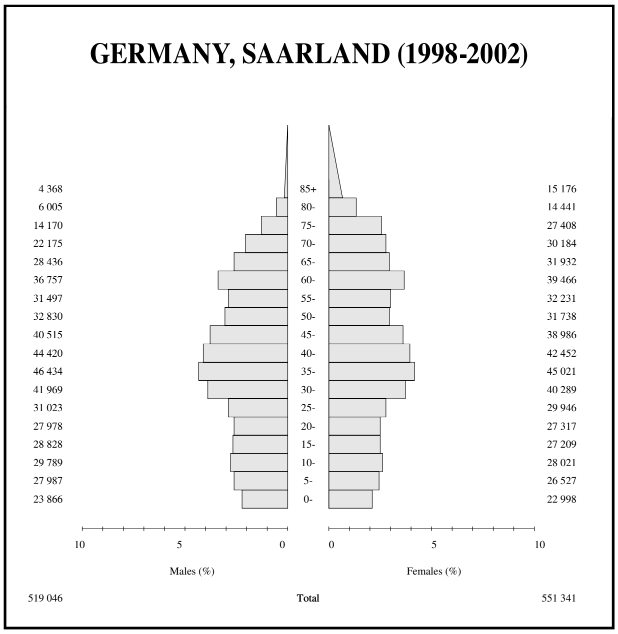
Germany, Saarland

Registration area

The Saarland Cancer Registry covers the population of the Federal State of Saarland. Located in the south-west of Germany between latitudes 49^{0}38’ and 49^{0}07’ and longitudes 6^{0}21’ and 7^{0}24’, bordering France and Luxembourg, Saarland is the second-smallest state in Germany. The area amounts to 2569 km^2 of hilly country with altitudes ranging from 150 to 695m above sea level. Saarland lies in the cooler part of the temperate zone, occupying an intermediate position between the oceanic climate in the west and the continental climate of the east. The average annual temperature is about 10^0 C. Average annual rainfall is about 1050 L/m^2.

The administrative structure consists of five counties and one metropolitan area, comprising 52 communities altogether.

The population of the Saarland is 1 070 102 (in 2000); 48.5% are males and 51.5% females, at a density of 417 inhabitants/km^2. Some 52.9% live in 13 conurbations of more than 20 000 inhabitants. Life expectancy for males is 75.0 years and 80.5 years for females. The overwhelming majority (72.7%) are Roman Catholic, with 21.7% Protestants and 5.6% with other/no religious affiliation. Of the total population, 92.5% are German and 7.5% possess foreign nationality. About 47.8% of Saarland residents are married, 36.8% unmarried and 15.4% widowed or divorced. The economically active population, 46.1% of the total, is employed in production industries (32.7%), distribution, transport and communications (23.6%), agriculture, forestry and fisheries (1.0%) and other sectors/ services (42.7%).



Cancer care facilities

Cancer treatment is carried out by both hospitals and private physicians. Treatment at the hospital level in Germany has been coordinated under a governmental programme structured on several levels. The ‘Tumorzentren’ (tumour centres involved in both research and treatment) cover large regions and are connected with big university hospitals. In the Saarland area there is one Tumorzentrum and one big university clinic. A series of regional hospitals dedicate considerable personnel and funds to cancer treatment. A small number of private oncological practices provide diagnostic and aftercare structures.

There are 27 hospitals with 8060 beds in the registration area. Hospitals comprise 144 special medical departments including four radiotherapeutic units. Morphological examinations and diagnoses are performed in eight pathological institutes, one specialising in neuropathology.

Registry structure and methods

The registry was established in 1967 in the State Statistical Office and is based on the Saarland Law on Cancer Registration, whose first edition came into force in 1979. A new, completely revised Saarland Law on Cancer Registration regulating and improving the use of personal data for epidemiological research, came into force in April 2002. Since April 2000 the registry has been an integrated unit of the Ministry of Public Health. Until 1999, it was financed by the Government of Saarland and by regular subsidies from the Federal Ministry of Health. Since 2000, it has been completely funded by Saarland State. Two full-time officers of health holding a university degree, two full-time registrars and three half-time clerks are affiliated with the registry.

The basic system of registration is centralised collecting of individual records including personal identifiers, which do not require the written formal consent of the registered patients. Notification is compulsory since 2002. Hospitals, physicians and persons acting on their behalf are obliged to report all newly diagnosed and treated cancer cases. In principle physicians must inform patients on the reporting to the registry, but there are some derogations. Patients have a right to withdraw from registration, but in practice withdrawal is extremely rare. Sources of information are hospitals, outpatient departments, pathology and radiotherapy departments and private practitioners. Death certificates are also used, and traced back when necessary.

Due to restrictive legal regulations, follow-up of patients is largely passive. Though all physicians treating cancer patients are generally requested to report any serious change in a patient’s health status, the registry is not allowed to conduct further enquiries. The files of the registered cases are linked annually with all death certificates.

Interpreting the results

Early detection and population screening activities in Germany started in 1971. Since programme restructuring in 1982, the population has been screened for cervix, breast, rectal and skin cancer. All tests are offered annually to eligible population groups, but there was no individually organised invitation by letter with location and time of testing. To date (September 2006) there is no regular PSA testing for men in Germany. Organised mammography screening for women from 50 to 69 years of age is currently to be established in all federal states of Germany.

Use of the data

The registry prepares annual reports of cancer incidence and mortality, and provides an interactive database (www.krebsregister.saarland.de) on the Internet. The registry carries out descriptive and analytical epidemiological studies, independently and in national and international collaborations.

Source of population

Estimate based on the 1987 census, making allowance for births and deaths, as well as for migration into and out of the registration area.

Multiple primary rules used

IACR rules (2004) on CI5 IX period.

Iceland

Registration area

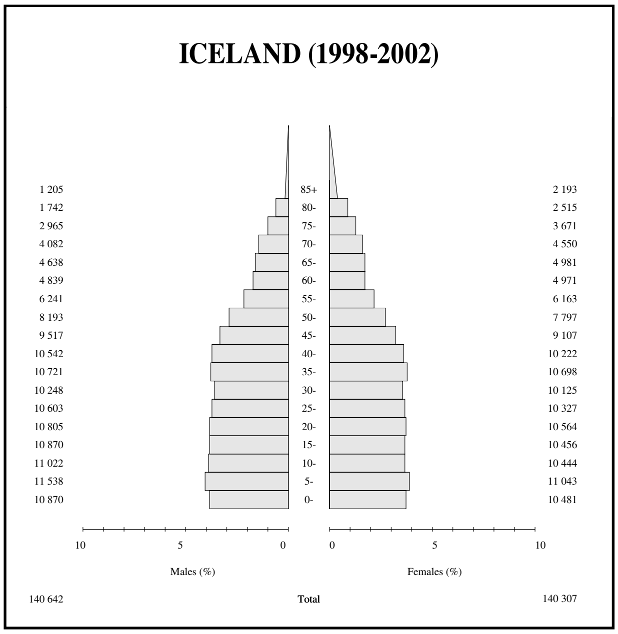
The Icelandic Cancer Registry is a population-based nationwide cancer registry covering the whole of the Icelandic population. Iceland is located in the middle of the North Atlantic Ocean between 64°–68°N and 14°–24°W. The geographical size of the country is 103 000 km^2. The Icelandic population is around 300 000 inhabitants.

Around 80% of the population is urban, and the urban population is mostly located in the southwest part of Iceland. The population ethnicity is northern European, and the religion is Christian Protestantism for the vast majority of the population.

Cancer care facilities

Patients in Iceland have easy access to physicians, whether in primary health care or consulting in a specific field of medicine. The healthcare system is a socialised system and the proportion of the cost of the healthcare burden laid on the individual or his private insurance is minimal.

Imaging facilities are available with highly sophisticated techniques both in the major hospitals and in private practice. There are four pathology laboratories in the country, one of which is purely for dermatopathology, and all of those provide the Cancer Registry with their valuable information. There are also well-equipped haematology and biochemical laboratories as well as a cytogenetic laboratory available for various investigations of patients. Cancer surgery in Iceland is for the most part limited to two hospitals, although minor surgical operations are performed both in private offices and in smaller hospitals. Specialised work on cancer treatment like neurosurgery and radiation treatment of cancer is centralised at Landspitalinn–University Hospital in Reykjavik.



A nationwide screening programme for cervical cancer has been operating since 1964 and for breast cancer since 1987. It has been decided that Iceland shall take up nationwide colorectal cancer screening in the near future. It is quite common for men above the age of 50 to have their PSA levels measured.

Registry structure and methods

At the request of the Director General of Health the Icelandic Cancer Society undertook in 1954 to establish and run a cancer registry. It has ever since been located at and run by the Icelandic Cancer Society. In recent years the Society has received a subsidy towards the cost of running the registry from the Icelandic government. A new law was enacted in 2007 which makes cancer registration in Iceland compulsory.

The core staff consists of a medical director, a managing director, two registrars, a computer technician, a data manager and a statistician. In addition there are part-time positions for 1–2 researchers.

The sources of data for the cancer registration are the pathology and haematology laboratories, all hospital departments and healthcare facilities. Registrations are also received from private-practicing consultants. Incomplete information is followed up by contact with the aforementioned institutions and individuals. The majority of the data is received in electronic form.

The first information on cancer cases in most instances (>95%) comes from pathology laboratories. Further information is then requested from all those who are likely to give additional details if needed.

The Icelandic Cancer Registry receives information from all death certificates from Statistics Iceland, where there is a mention of a malignant disease. The registry further checks this information and additional information called for if needed.

Periodically, all registration for each site is checked and discrepancies are further investigated. The IARC check program is used.

Use of the data

Figures on incidence, prevalence and survival are published every year in the yearbook of the Icelandic Cancer Society as well as on the home page of the Icelandic Cancer Registry (www.cancerregistry.is). The registry staff is actively engaged in epidemiological research on cancer, and the registry is also the source of data for such research conducted by others. The Icelandic Cancer Registry in addition provides information to assist public health officials in planning for both the prevention and treatment of cancer.

Source of population

The population–at–risk derives from the Icelandic National Roster, in operation since 1952 and regularly updated for births, deaths and migration.

Multiple primary rules used

IACR rules (2004) on historical data.

Notes on the data

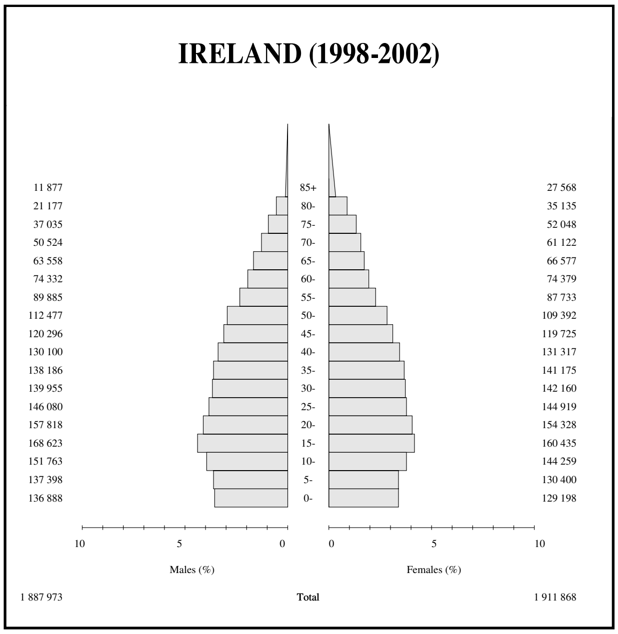
C44 does not include basal cell carcinoma.

Ireland

Registration area

The catchment area of the National Cancer Registry is the Republic of Ireland. A separate registry covers Northern Ireland.

The Republic of Ireland is situated between 51°30’ and 55°30’ N and between 6º0’ and 10º40’ W. The total land area is 70 282 km^2, comprising 83% of the island of Ireland, with a long indented coastline of 3169km. The highlands are mainly coastal, with a central limestone plain, and the country does not rise above 1040m at any point. The climate is temperate and oceanic, with average winter temperatures between 4°C and 7°C, and summer temperatures between 14°C and 16°C. Yearly rainfall is highest on the mountains of the west and lowest in the east midlands.



IRELAND (1998-2002)

The population at the 2002 census was 3 917 203 (1 946 164 males and 1 971 039 females). The population is predominantly native-born and Caucasian, but information on ethnicity is not collected either at census or by the Registry. Most of the population (88% at the 2002 census) are Roman Catholic. In 2002, 40% of the population lived in rural areas (centres with fewer than 1500 inhabitants).

Cancer care facilities

Cancer patients in Ireland can avail of either private or public health care. All public and private hospitals allow the Registry full access to case information. The majority of cancer patients (about 84% of incident cases) attend public hospitals. There are two main publicly-funded radiotherapy centres in Ireland, located in Dublin and Cork, and two smaller private centres both in Dublin. Almost all cancer treatment is provided within the country.

No co-ordinated screening programmes existed in Ireland in the period 1994–2000, but breast screening began in 2000 and by the end of 2002 covered approximately 50% of the population. It is hoped to have full population cover by the end of 2007. Opportunistic but unorganised cervical screening has existed for many years, but it is not possible to estimate the proportion of the population covered. In October 2000 the first phase of a national cervical screening program was established in one region of the country. PSA testing is common in the population.

Registry structure and methods

The National Cancer Registry was founded in 1991 and began collecting population-based cancer incidence data for the entire country in 1994. In 1991 it took over the functions of the Southern Tumour Registry, which had provided population-based registration for about one sixth of the country since 1975.

The Registry is administered by the National Cancer Registry Board, whose members are mainly medical practitioners, and is fully funded by the Department of Health and Children. The Registry has a staff of 42, 22 of whom are engaged in active data collection.

Reporting of cancer cases is not obligatory, and the Registry collects most of its information through active casefinding and data abstraction. Most notifications come from pathology departments, with a smaller number from other hospital sources, death certificates and GPs.

The Registry has full access to all death certificates issued in Ireland since 1994, and uses these for case-finding and follow-up. Death certificates are followed up with the hospital of death or the certifying doctor if the cancer is not already registered. Unconfirmed death certificates are registered as death certificate only (DCO). At present the Registry does not carry out active follow-up.

All data is extracted directly onto laptop computers and no paper forms are generated. The ICD-O-2 coding system is used for both topography and morphology. All malignant, *in situ* and uncertain cancers are registered, as well as benign intracranial and intraspinal cancers. CIN III of cervix is not registered on the basis of cytology, but only if confirmed by biopsy.

We have recently carried out a formal evaluation of completeness, using statistical methodology, in collaboration with Dr David Robinson of Thames Cancer Registry. Periodic checks for completeness are carried out against other cancer databases. We plan to carry out a reabstraction of a 2% sample of records next year.

Use of the data

Annual reports, with information on incidence, mortality, treatment and survival are produced. The Registry has also published a number of scientific papers and special reports on a number of different topics, a list of which is available on the website (www.ncri.ie/pubs/pubs.shtml). The data are also widely used in the Irish health services for service planning and needs assessment.

Source of population

For 1997–2001: Population and migration estimates (Each year the Central Statistics Office (CSO) publishes an estimate of the population at April of that year. This is based on the natural increase and on estimates of the gross annual migration flows). For 2002: Census 2002.

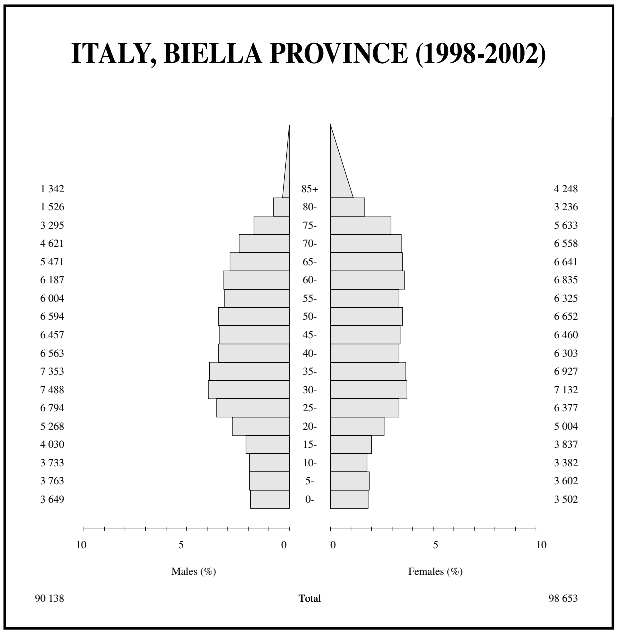
Multiple primary rules used

IACR rules (2004) on historical data.

Italy, Biella Province

Registration Area

The Cancer Registry covers an area with 82 municipalities: 22 have fewer than 500 inhabitants and 15 have a population between 500 and 1000 inhabitants. Most of the population (187 041 inhabitants in the 2001 census) resides in urban areas (24.3%). The textile industry had always been the main activity in the area; however, during the last 20 years other electronic and metal-mechanical industries have arisen. Due to its industrial background dating back to the 19th century, this area has always been a place of immigration. In the 1950s people arrived from the Northeast of Italy (about 20% of population now aged 60–80) while in the 1970s people migrated from the south of Italy. Migrations from other countries are only recent and limited to young people (<5% of population). The birth rate is rather low (7.36 in 2001) and the elderly index high (198.95 in 2004). Nowadays, there is relative demographic stability, especially in the valleys where the communities are more isolated.



Cancer care facilities

The registry area is served by one public hospital of about 500 beds with the main surgical and medical specialities, radiotherapy, oncology and a palliative care unit, and two private clinics. Population-based screening programmes have been active since 1997 for cervical cancer, and since 1995 for breast cancer, while in the previous years screening practice was rather diffuse although opportunistic. A multi-centre evaluation trial has been carried out for colorectal cancer screening using FOBT and endoscopy since 1997. Opportunistic screenings with PSA for prostate and with clinical skin examination for melanoma were carried out with the support of the local cancer foundations for the past few years.

Registry structure and methods

The registry is part of the Centre for Cancer Prevention (CPO) of the Piedmont Region, located in the Epidemiology Unit of the Local Health Authority (ASL 12), staffed by a director, a part-time public health doctor and a registrar nurse. The registry actively searches for cases in all clinical records of local hospitals and pathology laboratories. It also actively searches for patients who migrated towards other centres, mainly in Piedmont and Lombardy, as indicated by the reports originating from the regional hospital discharge records. The registry also double-checks data with other repositories of cancer data: the Piedmont Childhood Cancer Registry, the National Malignant Bone Tumour Registry and the Mesothelioma Piedmont Cancer Registry. If case confirmation or prevalence checks are needed, the registry's staff looks up other specific files of hospital departments (radiology, radiotherapy, oncology), laboratories, the palliative care unit (active since 2000) or the hospital cancer registry (active 1959–1997). Finally, the registry regularly receives records from the local official mortality registry and has access to original documents for further checks. Completeness and accuracy of the information are formally evaluated in several ways. After data verification with the IARC-Check tools, we analyse short-term trends in number of cases, percentage contributions of each information sources, cases with poor site or histological specification, microscopic verification, prevalence of multiple primary cases, mortality incidence ratio, and proportion of DCI and DCO.

Interpreting the results

Cancer incidence in the Province of Biella is influenced by its social and industrial history, with a high incidence of larynx, lung, oesophagus and stomach cancers in men. Recently, screening programmes have made an important impact, with increasing incidence rates for breast, prostate, and rectum cancers. Clusters of cases in a particular area (mainly thyroid cancer) are presently under study.

Use of the data

The Registry reports on incidence, mortality, survival and their trends to the local and regional authorities. In addition, it reports on hospital cancer patient migration and quality of hospital records. The Registry collaborates to the evaluation of cancer care quality and to the preparation of cancer treatment guidelines. It also provides a follow-up service for clinical and epidemiological researches, and is actively involved in the following studies: the Colon-rectal screening evaluation trial (SCORE), the evaluation of prostate screening, the evaluation of implementation of colon-rectal cancer treatment (TRIPPs) in collaboration with CPO, and the prevalence of anaemia in the elderly (ANGEM) in collaboration with the Mario Negri Institute. The Registry contributes its own data to the National Database of the Italian Association of Cancer Registry (AIRTum).

Source of population

Census 2001 and Intercensual estimates: Intercensual estimates with population as of 31.12 of every year are provided by the statistical office of the Piedmont region (BBDE). The registry provides the annual median population.

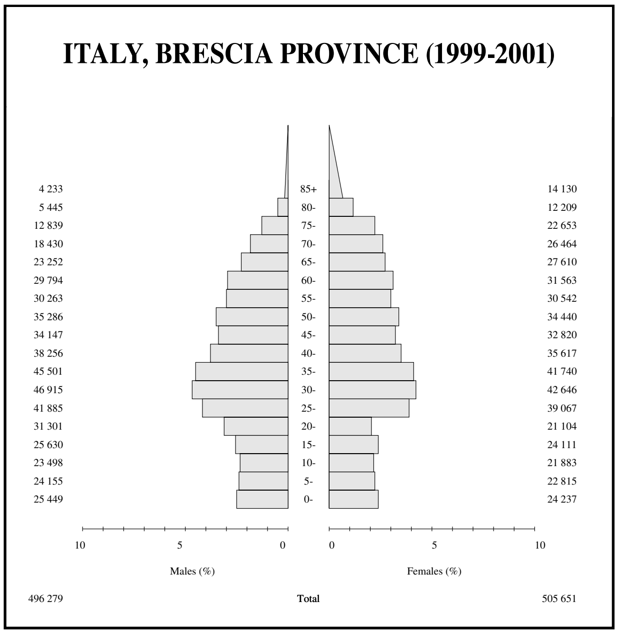
Multiple primary rules used

IACR rules (2004) on historical data.

Italy, Brescia Province

Registration area

Brescia is one of the most densely populated provinces in the Lombardy region of northern Italy. The Brescia Health Unit Cancer Registry covers about 91% of the population of the province. Registry data are available for 1993–1995 and for 1999–2001. The Brescia Health Unit Cancer Registry started in 1994 using manual methods, and covered a smaller area with about 390 000 inhabitants, consisting of the town of Brescia and 23 surrounding municipalities. The Registry currently uses an automated population-based cancer registration system. It covers an area of 3460 km^2 at 45°N latitude. It covers Brescia (population 195 000) and 163 other smaller towns, 55 with more than 5000 inhabitants (33.7%) and 108 with fewer than 5000 inhabitants (66.3%). The population was 1 004 980 inhabitants, 51% females, at the October 2001 census. The population density is 290/km^2.


ITALY, BRESCIA PROVINCE (1999-2001)

In 2001 about 8% of the population were foreigners: 30% came from East Europe and 70% from non-European countries (25% from Asia, 20% from North Africa, 20% from Sub-Saharan Africa, and 5% from South America).

Cancer care facilities

In the Registry area there are 12 public and 9 private hospitals; the largest, located in Brescia, has medical and surgical specialists and a Radiotherapy Department. The Oncology Department covers the Brescia province. In 2001 there were 3822 beds in public hospitals and 2365 in private hospitals (6.1/1000 inhabitants), and is 846 general practitioners (84.2/100 000 inhabitants). Brescia has had mammographic screening for women aged 50–69 years since the late 1980s.

Registry structure and methods

The Brescia Cancer Registry is located in the Brescia Local Health Unit (Azienda Sanitaria Locale, ASL), which provides financial support. The Registry is also funded by the non-profit Lega Italiana per la Lotta Contro i Tumori, Sezione di Brescia (Italian League Against Cancer, Brescia Division), and ASM S.p.A. (Public Utility Company). The ASL provides all the equipment and some of the human resources (4 nurses and a secretary); the two other founders support the activity of 1 medical doctor and 1 computer programmer. A medical doctor and university researcher also provide scientific support.

The Registry uses three computerised data sources: hospital discharge records provided by the Lombardy Region, pathology reports from 9 public and private laboratories, and death certificates provided by the Local Health Unit death registration office. All Italian hospitals must report each admission using a standardised form in order to receive payment. As the Regional Hospital Discharge Diagnosis Office collects all hospital discharge data from Lombardy and bordering regions, the proportion of cases missed is likely to be very small. Most pathological records are uncoded, and Registry staff code about 80% of them to ICD-O-2.

Computerised records containing all the collected data (hospital discharge records, pathological records and death certificates) are automatically linked to the Social Security System to assign a patient code to each record, and all records with that code are linked with prevalence files. Concordant incident malignant cases are assigned to the Registry. For discordant and incomplete cases, the Registry staff review the computerised information, and if any remain unresolved, they scrutinise hospital records and abstract information on cancer cases directly. For cases with death certificate notification, they trace-back and ultimately reister those that do not link with another source as death certificate only (DCO).

Completeness and accuracy of ascertainment of cases are provided through comprehensive computerised data sources and also through checking and comparison of incidence rates in previous years and with other registries in northern Italy.

Interpreting the results

Two findings from the Brescia data are high frequencies of liver cancer among men and breast cancer among women. A comparison with 1993–1995 data confirms these findings. In the last decade, epidemiological studies have been carried out to investigate the causes of liver cancer, mainly hepatocellular carcinoma, in the area; the role of hepatitis B and C viruses and of heavy alcohol intake have been elucidated. The breast cancer rate among women may be partially due to population-based mammographic screening in the area in recent years. Non-organized PSA testing concerns 12.56% of the male population (38.7% aged ≥50 years).

The Brescia province is a highly industrialised area, with one of the highest concentrations of steel and metalworking industries in Europe. Working in these factories has been associated with possible exposure to IARC class 1 and 2A carcinogens. Air pollution has been observed in the area, especially on the plain: the mean annual PM10 concentration ranged from 30–42 μ/m^3 and most daily values in the winter of 2004-2005 exceeded 75 μ/m^3.

Use of the data

The aim of the Registry is to produce and analyse incidence, mortality, prevalence and survival data according to demographic, topographic, morphological and behavioural characteristics. The Registry works alongside Regional and other Italian Cancer Registries in research projects and on publications of incidence, prevalence and survival data. A multi-centre national study coordinated by the Director of the Brescia Health Unit Cancer Registry and funded by the Italian Ministry of Research is being conducted on the prevention of liver cancer through improved control of hepatitis B and C. A programme for the prevention and control of liver disease by general practitioners is also underway. Registry data are used routinely for monitoring population-based cancer screening programmes in the Brescia Local Health Unit.

Source of population
The resident population is estimated annually on the basis of the 1991 and 2001 censuses, taking into account births, deaths and migrations, by the National Institute of Statistics (Istituto Nazionale di Statistica – ISTAT).

Multiple primary rules used
IACR rules (1990).

Italy, Ferrara Province

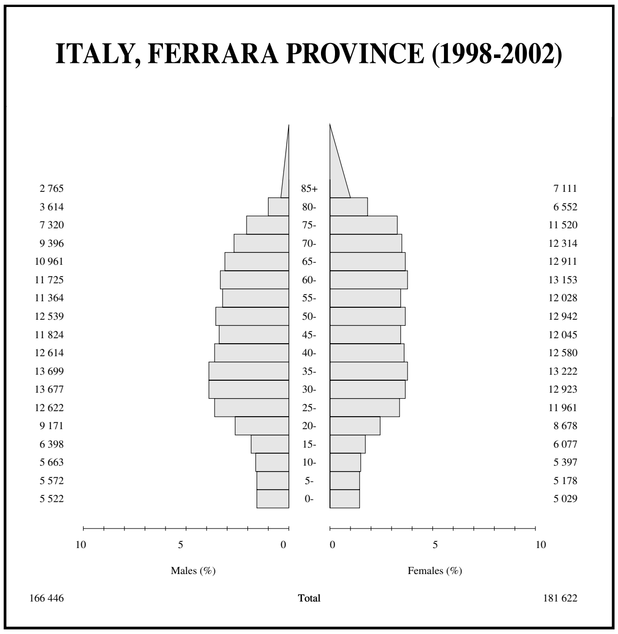
Registration area

The province of Ferrara is located in the northwest of Emilia-Romagna Region and is mainly agricultural. It lies close to sea level (maximum altitude 22m) and is bordered to the north by the Po River, to the east by the Adriatic Sea, to the south by the provinces of Bologna and Ravenna and to the west by those of Modena and Mantova.

The population (348 651 in 2000) is fairly stable, characterised by elevated aging (24% over 65 years) with a crude annual birth rate at the lowest levels in Italy (6.1/1000 inhabitants in 2000). Among the 26 municipalities of the province, the only one with a population >100 000 is Ferrara (132 085 inhabitants in 2000).

The prevalence of non-Caucasians is low, and the most widespread religion is Christian Catholic. The number of immigrants is lower than in other regional provinces, but the proportion increased in size from the late 1990s (from 0.52% in 1995 to 2.43% in 2004). A majority (54.5%) of them come from five countries (Morocco, Ukraine, Albania, Romania and Pakistan), and the female/male ratio is 1.23.

The level of employment was 47.8% (35.6% industry, 9.4% agriculture, 55.0% trade and services). Mechanical and chemical industries are present in the province, and they represent the main sources of water and air pollution, together with animal breeding, traffic, heating plants and agriculture chemical treatments. In 2000 the average temperature was 13.3°C (monthly average from –0.5°C in January to 23.8°C in August) and the overall rainfall was 443mm. In the period 1998–2002 the population showed a progressive decrease due to a fall in births and low migration rates from other areas.



Cancer care facilities

In 2000 the province had a network of three care districts with 5 general hospitals (1851 beds). These provided cancer surgery units, haematology, radiotherapy and chemotherapy services. Cervix uteri and breast cancer organised screening programmes started in 1996 and 1997 respectively as a part of a regional project. Colorectal cancer screening started in 2005. PSA testing is widespread among the adult male population, especially in recent years. In 2003, 14.6% of patients were treated outside the Registry area.

Registry structure and methods

The Registry is supported by the Emilia-Romagna regional Health Care Service since 1994, and it has also been funded by the Health Care Units of Ferrara province. Its staff of three clerks and a director is located in the Pathology Department of Ferrara University.

The main sources of information are discharge diagnoses from all national hospitals and the database of the Pathology Department (covering all pathological diagnostic activity in the province). Additional information is provided by direct contact with care services (medical records) and general practitioners. Mortality data for all causes are provided by public health services to identify DCN and DCO cases and for follow-up purposes.

Data collection is performed both actively and passively. Personal identifying data are protected in compliance with current Italian law. Regular maintenance is carried out on the computerised database. Checks for duplicates, errors and consistency are performed using the IARCcrg and DEPedits tools. Completeness and accuracy evaluations are performed using death certificates, record-linkage with pathological archives and checking of site-specific changes in incidence over time.

Interpreting the results

The high prevalence of old-aged population has a great effect on crude incidence rates of many sites. In the area covered by the Registry, lung cancer is traditionally the most common male malignant tumour. The rate of cigarette smoking in the Province (32.6% over 14 years old in 1996) is the highest in the Region (average 26.3%) and one of the highest in Italy. About 42% of children have at least one smoker parent. Air pollution from the aforementioned sources and fog also add further risk for lung cancer. Dietary risks are also remarkable, due to high meat, cold cuts and saturated fats intake, compared with low vegetable consumption. The province shows also high incidence rates for colorectal, gallbladder, soft tissue and endometrial cancers, brain tumours and multiple myeloma.

The very high incidence of breast and cervix cancer is explained by the population-based screenings started in 1996–97. Prostate and thyroid cancers also increased in the period, the former as a result of PSA diffusion, the latter of diagnostic echography improvement. DCN and “final” DCO were 1.1% and 1% respectively. The proportion of cancer deaths necropsied in 1998–2002 was low (<1%).

Use of the data

The Registry is involved in local and regional cancer care networks and it publishes periodic reports on cancer incidence, prevalence and survival. Determining the impact of screening on incidence, mortality and therapy and cancer care needs in the covered population are its main purposes. It is also involved in several studies on multiple tumours, the prognostic and predictive power of biological assessment in breast cancer, social inequalities and cancer care access.

The Registry is part of the Italian Association of Tumor Registries (AIRTum). Several studies on cancer descriptive epidemiology and breast cancer screening in Italy are now in progress. Further activities on registration and coding techniques are also being carried out.

Source of population
1998–2002: Census and municipalities' residents files. Official regional resident population based on municipalities' files. Source: Statistics Department Regione Emilia–Romagna, Italy (http://rersas.regione.emilia–romagna.it/statexe/popol1.htm).

Multiple primary rules used
IACR rules (2004) on historical data.

Italy, Florence and Prato

Registration area

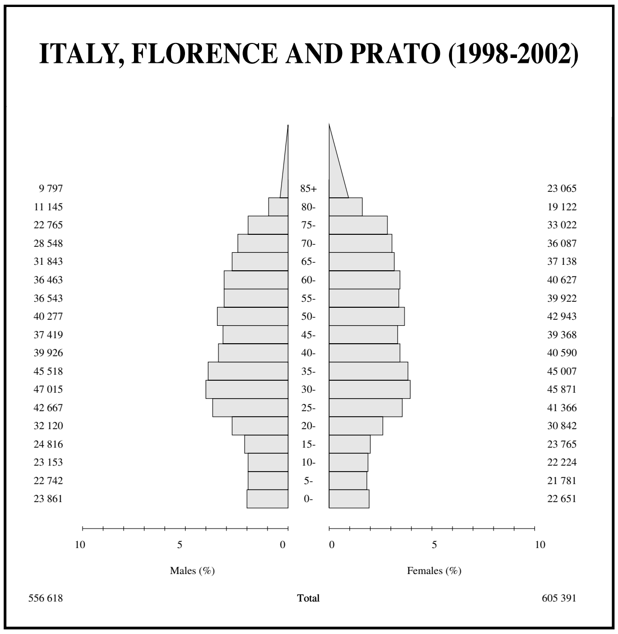
The territory of the Tuscany Cancer Registry (RTT) corresponds to two of the ten provinces of the Tuscany region, the provinces of Florence and Prato. It is situated at 44°N and 11°E. The registry covers an area of 3879 km^2, with a population of 1 162 273 inhabitants according to the 2001 census (density 300 inhabitants/km^2). The territory is divided into 52 municipalities (the municipality of Fucecchio, 21 105 inhabitants at the 2001 census, is included since 1997) collected in 3 local health units.

The only two municipalities with a population larger than 100 000 in 2001 were Prato (population 172 499) and Florence (population 356 118).

Catholicism is the prevalent religion in the area. About 4.1% of the residents (at 2001) in the area are foreign, mainly coming from Europe and Asia.

In 2001, 74.1% of the residents aged 15–64 years were employed. Industry in the provinces is concentrated mainly in the surroundings of the cities of Florence and Prato.

Since 2006 the RTT has been embedded within the regional oncological network, and the coverage of all the resident population of Tuscany (about 3 500 000 inhabitants) is ongoing.


ITALY, FLORENCE AND PRATO (1998-2002)

Cancer care facilities

The registry is part of the Tuscany Cancer Institute, a network of all health services active in the Tuscany region aimed at cancer research, prevention and care.

In 2002, in the whole Tuscany region there were 14 956 beds in public hospitals and 2353 beds in private hospitals. There were 4.9 beds for every 1,000 inhabitants.

Registry structure and methods

The Tuscany Cancer Registry is associated with the Unit of Clinical and Descriptive Epidemiology of the Centre for the Study and Prevention of Cancer (CSPO) in Florence. The registry, which is commissioned and funded by the Tuscany Region Department of Health, collects, registers and analyses information related to cases of cancer in residents of the provinces of Florence and Prato. The Registry started its activity on 1 January 1985 after a one-year experimental phase to evaluate feasibility and to collect prevalent cases.

While instituted by regional law, notification is compulsory by an administrative order.

The registry receives from the Regional Health Authority copies of the official files of hospital admissions in Italian public or private hospitals (provided the latter are funded by the Public Health system), which have been abstracted from pre-coded electronic media since 1995. Copies of the autopsies and cyto-histology referrals are received from the pathology departments of the whole Tuscany region. Since 1998 pathological data have been received on computerised files.

The RTT used ICD-O-1 and ICD-O-2; all case series have now been automatically recoded into ICD-O-3. The information concerning each tumour, including personal identification and full clinic details, is coded and registered into the computer. Specific procedures and key words protect the access to the RTT files; names and other personal data and clinical information are stored on different files and, when necessary, are linked each other by an identification number.

Death certificates with personal identifiers are received from the Regional Mortality Registry, which collects and analyses for all inhabitants in the region a copy of the National Institute of Statistics mortality form. Mortality data are periodically checked against the cancer registry records to identify cases not otherwise notified.

The current staff of the registry comprises clinical epidemiologists, nurses specialising in tumour registration, biologist, statisticians and data managers.

Interpreting the results

The completeness in case collection was estimated at 97.4% during a formal evaluation carried out in 2001. Data are periodically verified according to IARC tools and specific software developed by the Italian Network of Cancer Registries (AIRTum).

Since the late 1990s screening for female breast, cervix and colorectal cancer has been active in all areas covered by the RTT. From the regional report on screening activity, the average compliance was 67% for mammographic breast cancer, 45% for cervix uteri screening and 51% for colorectal cancer screening.

In the district of Florence a cohort of more than 6800 males aged 60–74 years were included during 1991–1994 in the European Randomized Study of Screening for Prostate Cancer (ERSPC). Moreover, widespread spontaneous PSA testing is worth noting; the regional archive of diagnostic examinations in 2004 estimated that about 25% of resident men over 50 had undergone a PSA test.

In the RTT area a pilot study of lung cancer screening with low-dose computed tomography has been performed, and a randomised clinical trial named Italung-CT is ongoing.

Use of the data

The registry routinely publishes incidence and survival data and participates in clinical and analytical epidemiological studies. RTT is improving the collection of relevant clinical data for the evaluation of the diagnostic and clinical pattern. It is participating in national and international projects on cancer incidence, prevalence and survival (e.g. the Eurocare project).

Source of population

1998–2002: Census 2001 and official intercensal estimates (ISTAT).

Multiple primary rules used

IACR rules (2004) on historical data.

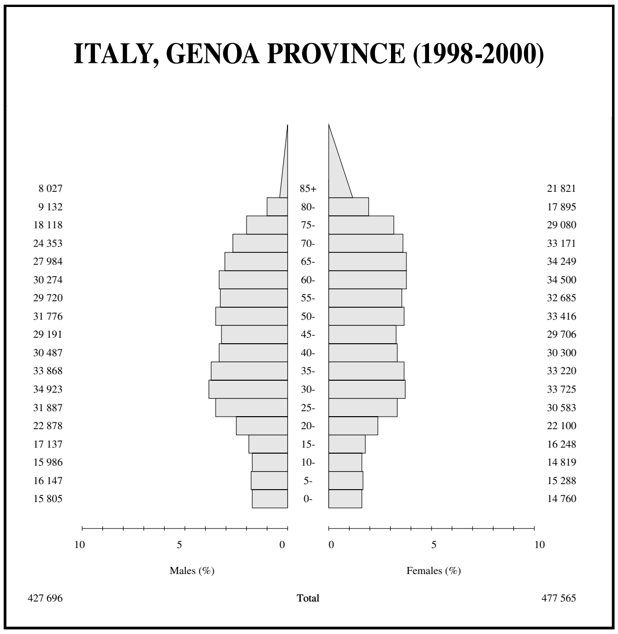
Italy, Genoa Province

Registration area

The Liguria Region Cancer Registry (LRCR) covers the population of Genoa Province (1834.3 km^2) within the Liguria Region in northwestern Italy. The population (67 municipalities) at 30 June 2000 was 900 736 inhabitants (Statistical Office of the Region of Liguria). About 70% of the population lives in the urban area of Genova (632 366 inhabitants). In 2002 the Liguria Region age-adjusted death rate per 100 000 inhabitants was 1370.1, among the highest in Italy, due to the ageing of the population, the oldest in Italy; the birth rate is among the lowest, 7.3.

Cancer care facilities

Healthcare services are provided by hospitals and centres located predominantly in the city of Genoa. They consist of 17 public and 4 private hospitals providing radiotherapy, cancer surgery and chemotherapy services, and microscopic verifications supplied by five pathology services. Among the public hospitals there is also a comprehensive cancer centre, the National Cancer Research Institute (NCRI)



Registry structure and methods

The LRCR is property of the Health Councillorship of the Liguria Region and is located at the Descriptive Epidemiology Service of NCRI, which is also houses the Liguria Region Registry of Cause of Death (LRDCR). The LRCR is staffed by eight full-time researchers and one clerk: two are coders; two manage the electronic records provided by the Ligurian Health Informative System (hospital discharge records, registers of population) and the pathological records, and perform the quality control and statistical analyses; four are registrars; the clerk is mostly engaged in following the cancer cases for vital status. They are also supported by a full-time researcher and two clerks from the LRDCR, who select the certificates of causes of death of each registered case.

The LRCR registry uses active case finding from various sources of data consisting of cancer hospitals (NCRI), general hospitals (13), teaching hospitals (St. Martino and University Clinics) and pathology laboratories. The registry staff visit these sources, where they scrutinise the records kept in medical records departments, and registers of individual departments concerned with diagnosis and treatment of cancers, to identify and abstract information on cases of cancer, diagnosed by all methods, among residents of the registry region. Arrangements have been made with the hospitals outside the registration area to collect the resident cancer cases they diagnose and treat; they are consulted once a year to ask for the clinical records of these cases. As regards as the mortality data, in addition to the LRDCR source, the registry also uses official mortality data obtained through the regional organs officially connected with the National Statistics Service (ISTAT).

Interpreting the results

The LRCR collects and records data on all malignant tumours and on *in situ* carcinomas and other tumours of benign and uncertain nature of the urinary tract, brain and central nervous system; multiple primary cancers (multiple skin cancers excluded) are included as independent primary tumours. The Registry uses the IARC/IACR CHECK Program to test the validation of dataset. To conform to the Italian law regarding the care of personal data, the Registry follows an Ethical Code of Behaviour (published in their Web site and sent to all collaborating institutions and to the National Authority for Individual Data Protection), created to describe the data collection and managing procedures and the physical and electronic measures adopted to protect the Cancer Registry data bank.

A screening programme for breast cancer has been operating since 1998, organised by the NCRI on the behalf of the Region Health Councillorship and collaborating with all hospitals, pathology departments and territorial health services of the region.

Use of the data

The LRCR is involved in the planning and evaluation of health programmes in the Ligurian Region. It also collaborates with the Italian Association of Cancer Registries on joint research efforts and publication programmes devoted to describe cancer incidence, mortality, and prevalence and survival data. With the same purposes, it actively contributes to many European projects (e.g. EUROCARE, EUROPREVAL, etc) aimed at analysing data on incidence, mortality, survival and prevalence (or their determinants) in Italy and in Europe. In these latter projects, the LRCR is interested in some specific research fields: the socio-economic determinants of cancer survival, cancer in the elderly, and the equity in care resources allocation. Recently, LRCR work has aimed at producing regional and national estimates of survival in the European population by using the demographic, socio-economic and clinical (Health System organisation) characteristics of each area.

Source of population

1993–2000: ISTAT for the Province

Multiple primary rules used

IACR rules (2004) on historical data

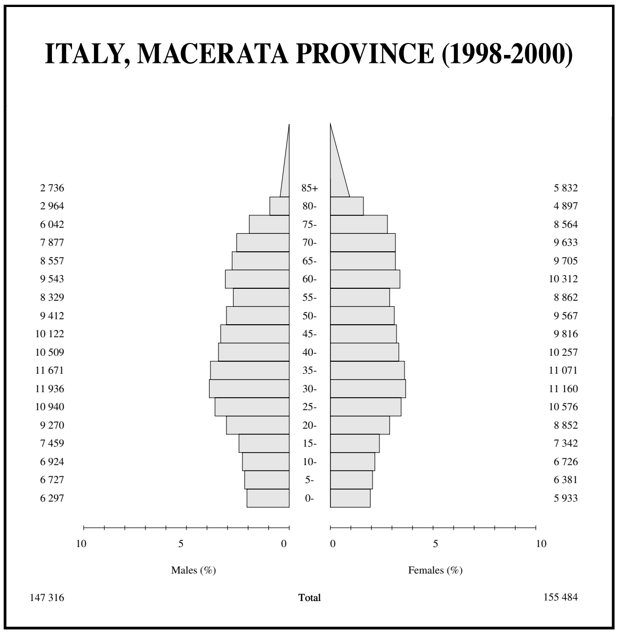
Italy, Macerata Province

Registration area

The Macerata province registry covers the population of the whole province (57 municipalities) ranging from a mountainous zone in the west to the Adriatic Sea on the east within the Marches Region, in central Italy.

The population at the recent cancer registry census (2000) was 304 443. Around 32% of the municipalities are located in the mountainous areas and have a low population density with a high proportion of people engaged in services. The 5% of municipalities situated in the coastal areas bordering the Adriatic Sea have a high number of people engaged in the industrial sector, and few in agriculture. Some 63% are located in the hill zone and can be characterised as intermediate between the other two zones.

Practically 100% of the population covered by the registry is white, with a small percentage of immigrants from China, India, Pakistan and Africa. The predominant religion is Catholic, but there are now also Muslim minorities.


ITALY, MACERATA PROVINCE (1998-2000)

Cancer care facilities

General health care in the province is provided predominantly by the three Local Health Districts (LHUs), through the district hospitals, a network of primary health centres and two pathology laboratories. This is supplemented by private practitioners and regional oncology hospitals. Each province in the region provides one radiotherapy centre. Many patients suspected to have cancer in the primary and secondary care facilities in the registry area are referred to Ancona regional hospital (40–90km distant), to Perugia regional hospital (80–130km, Umbria Region) or, occasionally to one of the cancer hospitals in northern Italy (e.g. Milano, Aviano).

Registry structure and methods

The registry (cancer and mortality) is located within the Department of Experimental Medicine and Public Health of Camerino University, and is funded partly by the Regional Health Agency. The registry is staffed by two epidemiologists and a registrar full-time; a doctor, a medical oncologist and a pathologist as consultants. The Macerata Cancer registry uses active case finding from different sources of data consisting of public and private general hospitals, pathology laboratories, radiotherapy centres, the Italian cancer registry and the death certificates from Mortality Registry of Macerata Province. This mortality registry receives copies of death certificates for all inhabitants from LHUs and a list of all deaths from the municipalities. The registry staff visit these sources and record diagnosis and treatments for every resident patient in the province. Cancer is not a notifiable disease; registration forms are not received from private practitioners. The information concerning each tumour, including personal identification and full clinical details, is coded and entered using the CanReg 4 computer program.

The accuracy of age, residential status and other demographic data are verified before records are included. The registry collects data not only on cancer incidence but also on diagnostic procedures, cancer characteristics (including stage and grade), treatment and survival. Follow-up is performed to obtain complete registration information and documentation on all cases.

Interpreting the results

Screening for breast and cervical cancer has been implemented in the province by the Sanitary Service, but the magnitude of these practices is as yet unknown. PSA is used frequently, but it is not possible to determine the proportion of the male adult population screened.

Use of the data

Information on incidence, prevalence, survival and mortality are produced and used in the LHUs and in the Regional Health Agency for service planning and needs assessment. The data are also sent to the Italian Cancer Registries' databank. The registry collaborates with some other registries in research projects and publications. Registry data are used to monitor cancer incidence and mortality in the province, as well as for health service planning and epidemiological research.

Source of population

1991 and 2000 censuses. Cancer registry personnel census the population as of 31 December of every year through the Municipalities.

Multiple primary rules used

IACR rules (2004) on historical data.

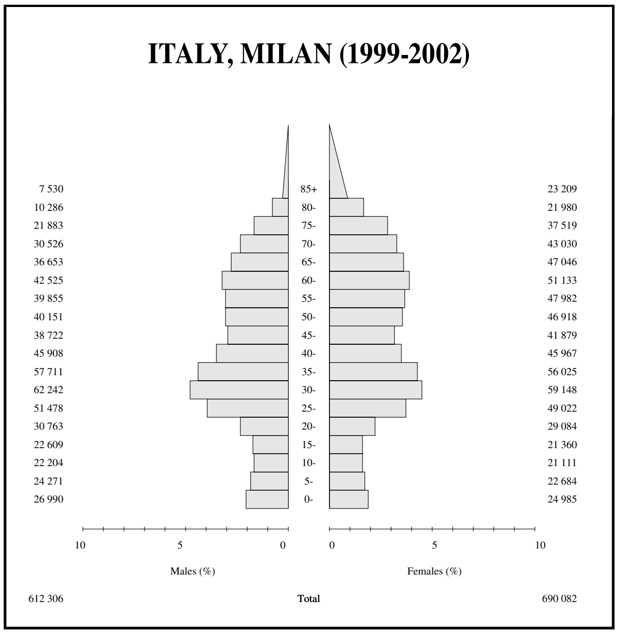
Italy, Milan

Registration area

The Milano Cancer Registry refers to the resident population of Milano, the largest metropolitan town in northern Italy (Lat. 45° 27' N; Long. 9° 10' E), covering a total area of 182 km^2. The population at the last 2001 census was 1 263 158 inhabitants with a population density of 6940/Km^2. At the last census 87 590 subjects (6.7%; 42 146 males and 45 444 females) were immigrants originating from Asia (30 116), Africa (19 481), South America (17 873) and Europe (19 950).

Cancer care facilities

A single Local Health Authority serves the population area. In the registration area there are 29 hospitals, which allow full access to case information. Among them, two research hospitals (National Cancer Institute of Milan and European Institute for Oncology) admit only oncological cases. A very small proportion of cancer cases are treated outside the Lombardy region.



Registry structure and methods

The cancer registry is located in the Epidemiology Unit of the Local Health Authority of Milano; it was established in May 2002 in adherence to the Regional Health Plan and funded by the Lombardy Region Department of Health. The registry employs three medical epidemiologists and four nurses as cancer registrars.

The registry is based on the automated cancer registration procedure (ACR) first adopted in Italy by the Venetian Tumour Registry and by the North East Cancer Surveillance Network. Accordingly, the resident population roster, death certificates, hospital/day-hospital discharges and pathology records archives are fed into the information system of the cancer registry.

The underlying cause of death and hospital admission diagnoses are coded in ICD-9. Pathology records are coded in SNOMED, and *ad hoc* transcoding algorithms from SNOMED to ICD-9 were developed and implemented. A total of 524 722 hospital/day-hospital discharges (1990–2003), 289 980 pathology records (1976–2003) and 18 295 death certificates (1999–2002), corresponding to 281 635 subjects, were considered in estimating the population incidence of cancer in the period 1999–2002.

Overall the automated procedure identified 165 614 prevalent cancer cases, 66 485 in situ/benign neoplasm; accepted 24 841 invasive cancer cases and temporarily rejected 24 695 cases. After manually resolving rejected cases, 39 404 incident cases were identified. Manually resolved cases, as well as all automatically detected genitourinary, haematological and soft tissue neoplasms, were coded with ICD-10 for topography and with ICD-O-3 for morphology. For selected cancers (including breast cancer) stage was systematically recorded.

Interpreting the results

Population-based breast cancer screening was initiated in Milano in November 1999. Furthermore, opportunistic PSA screening for prostate cancer was extensively adopted in the same period: 26.9% of male population aged 40 or older with no history of prostate cancer have received at least one PSA test in 2 years; the same rate rises to 34% for subjects older than 50 (*J Med Screen. 2002;9(4):179-80*).

Use of the data

The Milano Cancer Registry will be used to evaluate breast and colorectal cancer screening programmes. Furthermore, policymakers use registry data to evaluate healthcare and cancer treatment policies and to plan prevention activities. Considering the high proportion of immigrants, registry data will be also used to study differential cancer risks within the resident population and to plan differential preventive actions.

The registry supports etiological research. Cases are followed annually to determine survival, taking advantage of a consolidated record linkage between the registry database and the Municipal Census Office.

Source of population

Annual estimates based on the 2001 census, taking into account births, deaths and migration, were produced by the Ufficio Sistemi Statistici del Comune di Milano (Municipal Office of the National Institute of Statistics – ISTAT).

Multiple primary rules used

IACR rules (2004) on CI5 IX period.

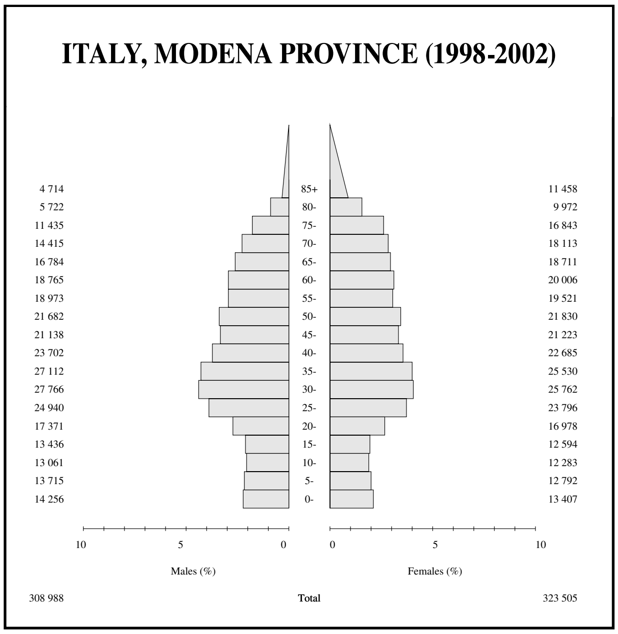
Italy, Modena Province

Registration area

The Modena Cancer Registry (MCR) covers the population of the province of Modena, which is one of the nine provinces of the Emilia-Romagna region in northern Italy. Modena borders the provinces of Bologna to the east, Lucca and Pistoia to the south, Reggio Emilia to the west and Mantua and Ferrara to the north.

The population according to the 2001 census was about 634 000 (growing by about 1% every year). Approximately 7% of all residents had emigrated from other countries (34% from northern Africa, 19% from Asia, 18% from Eastern Europe, 14% from the European Union and 11% from West Africa).

The province is divided into 47 municipalities. The only municipality with a population greater than 100 000 is Modena (about 175 000 inhabitants in 2001).



Cancer care facilities

With respect to health services, the province of Modena shows the features typical of most western countries. The area is served by 9 public general hospitals, including one university teaching hospital, and by 5 private clinics.

The university hospital also includes a Comprehensive Cancer Centre (Centro Oncologico Modenese).

Registry structure and methods

The MCR, established in 1988, is located in the Cancer Centre of the University of Modena and Reggio Emilia. It is recognised and supported by the Emilia-Romagna region, the Azienda USL of Modena and the “Angela Serra” Association for Research on Cancer.

Registry staff comprises a medical director and coordinator, a research manager, a statistician, a system manager, two registrars and a secretary.

The principal data sources are the reports from the three pathology laboratories located in Modena (including one haematological laboratory), hospital discharge files and death certificates. These files are periodically sent to the registry and processed by specific software. All cases are identified and pre-coded by the computer system, and then the trained registry staff manually reviews them. Several validation checks are performed by the computer system at the time of data entry, and periodically over the whole archive.

The registry mostly carries out follow-up by matching registrations with notifications of death and with public health databases. Only non-matched patients (less than 1%) are actively followed-up by obtaining information directly from the registry offices.

All data are evaluated for completeness using IARC software and a tool developed by Modena Cancer Registry and distributed among Italian Cancer Registries that consists of more than one thousand internal checks.

Interpreting the results

Since 1994, two organised screening programmes have been offered to all women aged 24–64 and 50–69 respectively for early detection of cervical and breast cancer. The impact of cervical screening seems to be less marked because it was carried out many years earlier, but not on population basis.

It should be underlined that the increasing use of PSA testing has resulted in an increase in prostate cancer incidence rates, while the advances in diagnostic medical practices and new histological criteria seems to be related to an increasing incidence of thyroid cancer in the province of Modena.

Use of the data

The MCR produces annual reports on cancer incidence, mortality and survival, including trends and predictions of cancer incidence and survival for the coming years. The MCR is involved in many collaborative studies, such as EUROCARE studies. The registry also participates in the evaluation of breast, cervix and the recently organised colorectal screening programmes. Other areas of interest are: the investigation of local clustering of disease, estimations of future cancer incidence and survival, high-resolution studies on lymphoma and myeloma, and quality control techniques.

Source of population

Census 2001 and population estimates for 1998–2000 and 2002 (ISTAT).

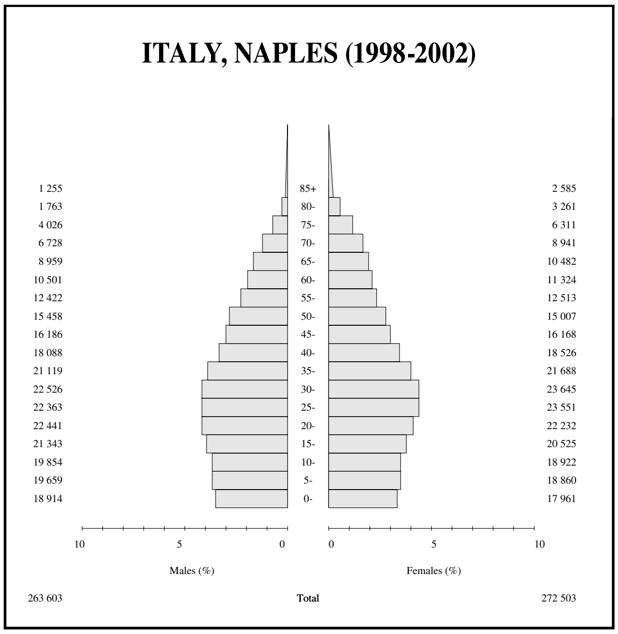
Multiple primary rules used

IACR rules (2004) on CI5 IX period.

Italy, Naples

Registration area

The Population Cancer Registry of Campania Region c/o Local Health Unit Napoli 4 (R.T.P.-A.S.L. NA4) covers an area of 499 km^2 in the northeast part of the province of Naples, in the Campania region of southern Italy (latitude 40° 47' N; longitude 14° 23'). According to the national census of 31 October 2001, the population covered by the Registry is 537 860 inhabitants (264 472 males and 273 388 females) distributed in 35 towns. In the last ten years the area covered by the Registry has been characterised by significant migration from Naples, which is the largest and most important city in the region. In fact, between the national census years of 1991 and 2001 the population of the area covered by the Registry increased by 45 000 inhabitants. In the area, which is economically depressed and characterised by high unemployment, there are a vast rural zone, an industrial pole with large and middle-sized factories, and also small-sized disorderly distributed factories.



Cancer care facilities

In the area covered by the Registry there are two public general hospitals with two chemotherapy services, one pathology laboratory and one private radiotherapy service having an agreement with the Public Health Service. The majority of resident patients who are affected by oncological diseases (about 80%) seek care in Naples, about 10km away, at the National Cancer Institute, at the two University Faculties of Medicine and at the oncology departments of other hospitals in the city. Though it is decreasing, there is still migration from the area to health services located in Northern Italy for the treatment of oncological diseases. In the same area, and over the whole Campania Region, there are also many private hospitals having an agreement with Public Health Service, in which patients affected by cancer are admitted. All patients affected by oncological diseases are exempted from bearing health participation expenses, and all patients who are admitted to hospitals abroad are previously authorised and registered by the A.S.L. NA4 offices.

Since April 1996, screening for uterine cervix carcinoma has been active over the entire Registry area, while breast cancer screening has been active since November 1998 over a limited part of the area covered by the Registry.

Registry structure and methods

The Registry is a structure of Campania Region and A.S.L. NA4; The Registry personnel is composed of a physician, specialising in oncology and epidemiology, one informatics technician and four social workers. Data collection method is active, and the sources of information are:

- Case sheets, clinical records and pathology laboratories' data, supplied by: a) National Cancer Institute of Naples, b) the two University General Hospitals, c) the Campania Region hospitals; d) the biggest private hospitals in the region;
- Regional Centre of Hospital Discharging Forms (SDO), which also provides data referring to patients who are admitted in other Italian regions;
- A.S.L. NA4 registries referring to patients who are exempted from bearing health participation expenses because of oncological diseases;
- A.S.L. NA4 records referring to admissions abroad;
- General practitioners of the area covered by the Registry (about 480) consulted for DCN cases; and
- Mortality data coded by the ASL NA4 epidemiology office.

Registry personnel have access to both the official mortality statistics and to individual death certificates mentioning cancer. Incidence cases are coded by Registry personnel. Malignant tumours included in incidence figures are defined as those for which the ICD-O-3 behaviour code is 3, and according to the IARC-IACR rules. Mortality data are coded and provided by the A.S.L. NA4 epidemiology service; they are defined as those coded in sections 140–208 of ICD-9. The software used for the registration of incidence data is CANREG-4, which is provided by IARC._

The Registry prepares periodical reports of cancer incidence, mortality and survival; moreover, it collaborates with public health services in the planning and evaluation of cancer services.

Source of population

Intercensal estimate for 1997–2000 (ISTAT), national census for 2001 and postcensal estimates for 2002 (ISTAT).

Multiple primary rules used

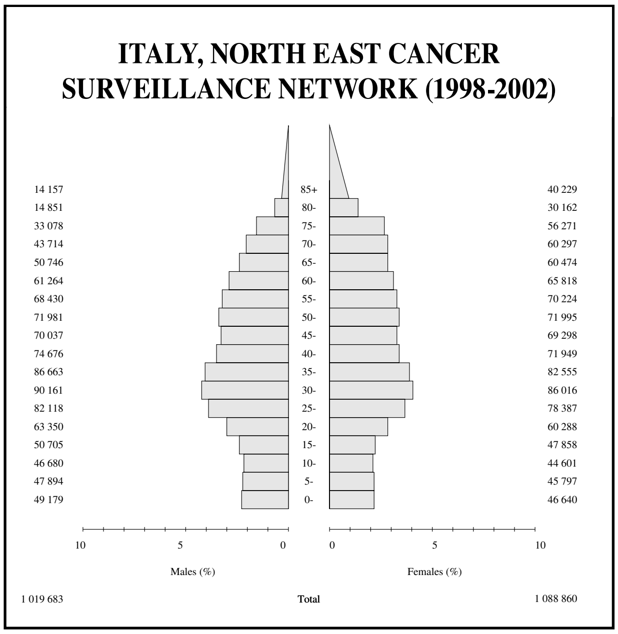
IACR rules (2000).

Italy, North East Cancer Surveillance Network

Registration area

The area covered by the North East Cancer Surveillance Network (NEICSAN) is located in northeast Italy, and is made up of three parts: the provinces of Bolzano (46°03'N, 13°14'E; 7400 km^2; 485 042 inhabitants; 65.5 inhabitants/km^2) and Trento (46°04'N, 11°08'E; 6202 km^2; 499 321 inhabitants; 80.5 inhabitants/km^2), and the whole of the Friuli Venezia Giulia region (46°03'N, 13°14'E; 6845 km^2; 1 184 000 inhabitants; 173.0 inhabitants/km^2).

The provinces of Trento and Bolzano are mostly mountainous areas, while the Friuli Venezia Giulia is a largely industrialised region bordered by the Adriatic Sea and the Padanian Valley (South), Slovenia (East) and Austria (East, North-East). Approximately 50% of the population of Trento and Bolzano and 80% of population of Friuli Venezia Giulia lives in urban areas (largest cities are Trento with 112 142 inhabitants, Bolzano with 98 657 and Trieste with 242 235). In addition to industry in the Friuli Venezia Giulia region, agriculture and tourism represent the main economical activities of the whole area, with low unemployment rates by Italian standards (between 2.7% and 6%). In the Bolzano province, 68% of the population is German-speaking.



ITALY, NORTH EAST CANCER SURVEILLANCE NETWORK (1998-2002)

Cancer care facilities

The territory is divided into 11 local health units of variable size, being smaller in the mountainous area. Hospital services are provided by 35 public hospitals (including one National Cancer Institute in Aviano, Friuli Venezia Giulia) and 16 private clinics. Cancer patients are generally treated at the National Cancer Institute, and in the oncology and radiotherapy departments uniformly distributed throughout the territory. A small proportion of cancer patients are also treated outside the region, including Innsbruck (Austria) for some patients from the province of Bolzano.

Registry structure and methods

The NEICSAN is a collaborative network of cancer registration in three administrative units: Azienda Sanitaria di Bolzano, Registro tumori dell'Alto Adige-Tumorregister Sud Tirol (1 director, 1 pathologist, 1 statistician/IT manager, 1 data collection officer and 5 collaborators); Agenzia Regionale della Sanità, Udine, Friuli Venezia Giulia (1 director, 1 pathologist, 1 data manager, 2 statisticians, 2 data collection officers and 5 collaborators); Azienda Provinciale per i Servizi Sanitari, Osservatorio Epidemiologico, Trento (1 director, 1 pathologist, 2 statistician/it manager, 1 data collection officer). In the Friuli Venezia Giulia region, cancer registration began in 1984 in the province of Trieste, and it has been expanded to the whole region since 1995.

The objective was to produce comparable cancer incidence estimates in a large population (about 2 150 000 inhabitants). Incidence data have been collected using the automated cancer registration (ACR) methodology, which implies availability of computerised and coded (ICD and SNOMED) diagnoses of cancer from the pathology departments, hospital archives and population offices (for population files and death certificates). The process is carried out through record linkage procedures that include analyses of computerised records, ascertainment of prevalent cases, case consolidation and quality control. Traditional cancer registration techniques based on collection of cancer forms prepared by pathologists, medical personnel in the hospitals and general practitioners are still used in the Province of Bolzano, where the ACR process has been carried out in parallel to the existing system.

For the period 1998–2002, a total of 9 461 762 records were treated by the automated process. Approximately 20% of these records concerned cancer cases, and the automated process registered nearly two thirds of incident cases. Quality controls are based on the IARC Check software: quality indicators such as the percentage of microscopically verified cases (histology and cytology), the percentage of cases known from the death certificate only (DCO) and the mortality/incidence ratio are also verified.

Interpreting the results

Several analytical studies conducted in the Friuli Venezia Giulia region have shown cancer excesses associated with personal habits and occupational exposures (namely exposure to asbestos in the shipbuilding industry). Incidence rates for the period 1998–2002 well reflect these previous findings. Changes in smoking habits in recent decades are a likely explanation for diverging trends in lung cancer rates seen in the two sexes, with a decline observed in men (from 56.3 in 1995–1997 to 49.1 in the most recent period) and a slight increase in women (from 11.3 to 12.0). PSA testing has been widely used in men for voluntary testing. Accordingly, prostate cancer turned out to be by far the most frequently diagnosed cancer in men (69.3/100.000; it was 51.6 in 1995–1997).

Use of the data

The main task of the NEICSAN is to help plan careful surveillance and preventive programmes. In addition, the registry data are used to implement population-based intervention studies (e.g. Pap smear and cervical cancer) and investigations on the causes of cancer (e.g. alcohol consumption and risk of liver cancer).

Source of population

Annual estimates based on the 1991 and 2001 censuses, taking into account births, deaths and migration, produced by the Ufficio Sistemi Statistici (National Institute of Statistics, ISTAT).

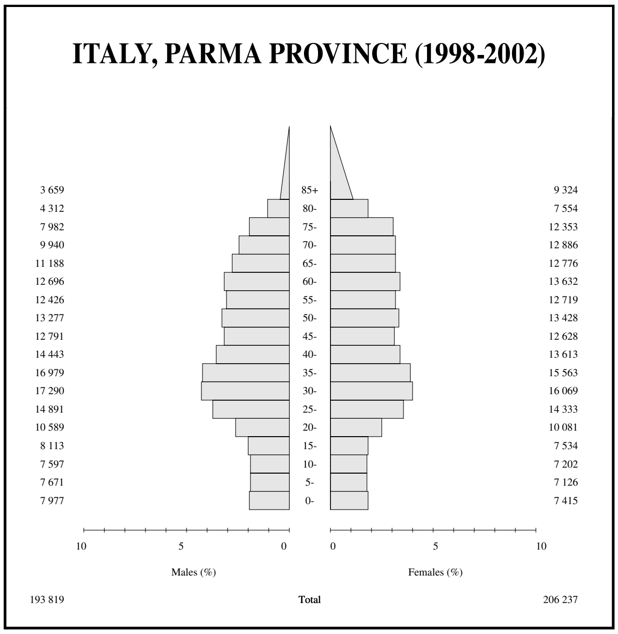
Multiple primary rules used

IACR rules (2004) on historical data.

Italy, Parma Province

Registration area

On 1 January 1998 the population of the registry area was 393 963; five years later it was 404 722. This increasing trend is mainly related to foreign immigration; overall foreigners, most from North Africa, currently represent 5% of Parma residents. About 80% of the population lives in urban areas, 43% in the principal town. Local migration from the mountainous municipalities towards the city has been steady since the 1970s. In 2001 the employment rate was 74% for men and 55% for women, while unemployment was respectively 2% and 4%. The main occupational group is tertiary (59.4% of the total employed population), followed by industry (37.4) and agriculture (3.2%). The industrial sector employs workers primarily in the agro-alimentary branch (45%), followed by manufacturing (15%) and building (15%).



Cancer care facilities

The area is served by one main general university hospital, two small public hospitals and three private ones; the hospital of Parma houses a division of Medical Oncology, including a section for cytopathological diagnosis, and a radiotherapy Service.

Registry structure and methods

The PCR is located at the Medical Oncology Division of the local hospital; the staff is made up of a medical doctor as Director, a statistician as data manager, and a full-time biologist for collecting and decoding data. Information regarding new cases is obtained through examination of discharge forms from public and private hospitals (representing the first level of information for each case, independent from the hospital where each patient was treated), oncological outpatient clinics, day hospitals, death certificates, and from the two archives of pathology services. The staff has direct access to the public pathology archive; the private hospitals annually provide the registry with electronic data. For extra-provincial hospital discharges, diagnoses are detected through an official inquiry to the department's director, or consulting the patient's family doctor by written request. Patient vital status is easily updatable, since PCR has access to the computerised registry database of the Local Health Service.

Data are regularly submitted to IARC Check program. Complementary evaluations have been made to compare our data (incidence trends and crude rates, percentage of MV/Dco, relative and observed survival rates) with those of neighbouring registries, and to examine the main features of special sub-areas of Parma Province (urban/rural area, altimetric zone, health service districts, etc.).

Interpreting the results

Two screening services began to operate in the area of registration: the population aged 50–69 has been screened for breast cancer since 1997 and the population aged 24–67 for cervical cancer since 1998. Some recent, increasing trends of incidence—breast and prostate cancer—reflect the diffusion of early diagnosis due to voluntary screening and asymptomatic forms through PSA testing. Trends in melanoma can be interpreted as being related to previous underestimation. M/I ratio offers an encouraging sign of the level of completeness obtained for each site. PCR continues to integrate and correct data previously collected.

Use of the data

Study data are aimed on one hand to promote the comparison of data and collaborative studies with other Cancer Registries, and on the other to support Health Services programming by estimating and quantifying the cancer burden.

Source of population

Estimates (ISTAT http://www.istat.it).

Multiple primary rules used

IACR rules (2004) on historical data.

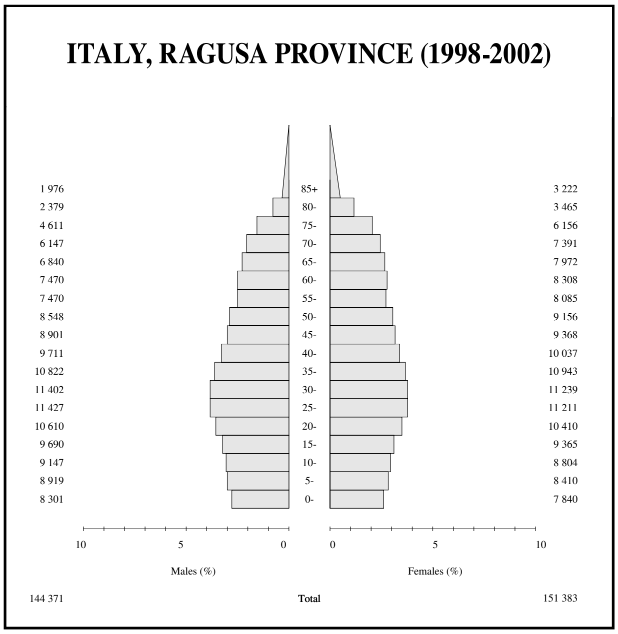
Italy, Ragusa Province

Registration area

The Ragusa Cancer Registry (RCR) covers the population of the province of Ragusa in southeast Sicily (Italy). At the 2001 census the population was 295 264 (5650 of whom were migrants, mainly from North Africa) living in small to medium-sized municipalities: the largest is Ragusa city, with 68 000 inhabitants; 9 cities consist of 8000 to 50 000 inhabitants, and in two villages the population accounts for 3000 people. Almost all people are white and Catholic; about 20% of the working population is involved in agricultural occupations (mainly farming and cattle).

Cancer care facilities

The local health system is arranged in one Main Hospital (Azienda Ospedaliera “Civile M.P.Arezzo”, Ragusa), one Local Health Authority (AUSL 7) that includes one private and 4 small public hospitals, and 350 general practitioners. There are two histopathological units, one oncological department and one radiotherapy unit; all of the public radiological departments have CT facilities, and the main public hospital provides MRI exams. All of the 7 surgical units of the local hospitals provide cancer surgery. A district-based breast cancer screening programme was established in 1995, covering half of the province’s female population aged 50–69 years.


ITALY, RAGUSA PROVINCE (1998-2002)

Registry structure and methods

RCR is part of the Oncological department of the main hospital (Azienda Ospedaliera “Civile M.P.Arezzo”, Ragusa). It is funded by the hospital itself and the Sicilian Government. The staff consists of a half-time medical doctor pathologist (director), two full-time social workers, and 12 part-time collaborators. Cancer registration is essentially an active process by means of field workers who abstract the required information from hospital admission/discharge files and clinical notes; case finding is also performed at pathology laboratories, radiotherapy units, oncological outpatient clinics and the local private TC centre (CITC srl Ragusa); a notable source of cases are the administrative offices that deal with cancer patients’ needs (i.e. exemption from cancer care and diagnostic charges). The local vital statistics and death registration offices provide RCR with all death certificates where cancer is mentioned. Municipal registers are involved for validation of the identity and residential data of each registered case, and checking vital status.

Ragusa Cancer Registry is carrying on a linkage study in order to evaluate the completeness of registration by comparing the records already detected from clinical notes with the Sicilian computerised hospital discharge recording system; the latter is an independent source of data that includes all hospital discharges of all of the patients resident in Ragusa province who were admitted in any Italian hospital.

Interpreting the results

Cancer occurrence in Ragusa province has been slightly increasing in the last ten years, but this area is still at a lower cancer risk in comparison to other registries from western countries. This is mainly attributable to Mediterranean dietary habits and to a lesser extent to the un-polluted environment. Despite this low risk, the 5-year relative survival ranks among the lowest in comparison to North European cancer registries; this low survival seems to be related to an advanced stage of the tumour at diagnosis.

The main change in the period 1998–2002 that may have affected cancer registration was the settlement of the radiotherapy unit and public CT facilities: this has made it possible to retrieve core cancer data like anatomic site, histological reports and stage at a more detailed level.

PSA testing has become more common since 2000, and prostate needle-biopsies have been increasing from year 2001 according to the data of the local surgical pathological laboratories; these practices may have slightly affected the local prostate cancer occurrence in the period 1998–2002.

Use of the data

Data are sent to the Italian Association of Cancer Registry, which publishes periodical national reports including specific tables of RCR. RCR is a collaborating centre for the European Prospective Investigation into Cancer and Nutrition (the EPIC study), and a partner and member of the EUROCARE and EUROCHIP studies and the EU-funded research EPIC-ELDERLY, the EU integrated project INTERACT and EU-coordinated action HECTOR. RCR data have been used for evaluation of the local breast cancer screening programme (the Italian IMPACT study).

Source of population

Intercensus estimate by Italian Institute of statistics (ISTAT) for 1992–2000, census for 2001, intercensus estimate by Italian Institute of Statistics for 2002.

Multiple primary rules used

IACR rules (2004) on historical data.

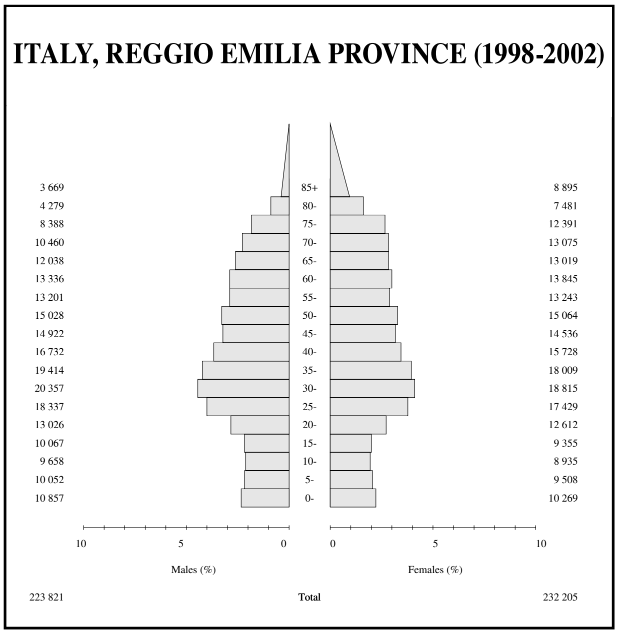
Italy, Reggio Emilia Province

Registration area

The Reggio Emilia Cancer Registry (RECR) covers the population of Reggio Emilia Province in the centre of the Emilia-Romagna Region, in north Italy. Reggio Emilia is characterised by an interesting and varied landscape that ranges from the vast plain in the North, where the main Italian river (Po) flows, to the Apennine Mountains in the South, which reach a height of 2150 meters.

The territory is divided into 45 municipalities, the principal one being Reggio Emilia, which accounts for more than 142 000 inhabitants.

The total population at the end of 2003 was 477 534; foreign residents represented 6.4%. The most common foreign groups came from North Africa, Eastern Europe and Central-South Asia.



Reggio Emilia is a highly industrialised area: the principal industries are mechanical and ceramics production, although agriculture is also present.

Until the late 1980s, some of the most important Italian asbestos cement factories were in this province, although the number of workers employed there was limited.

Cancer care facilities

Public healthcare is provided by the territorial-based Azienda USL and the Arcispedale Santa Maria Nuova (ASMN) hospital. The Azienda USL is divided into 6 healthcare districts, each with its own hospital. The ASMN includes several healthcare facilities: oncology and radiotherapy departments (both since the 1970s), digestive endoscopy, dermatology and pathology departments. In each healthcare district there is a medical oncology unit.

At present, there are three working screening programmes in the province of Reggio Emilia: for breast and cervix cancers (since 1994) and for colorectal cancer (since 2005).

Registry structure and methods

The RECR is recognised and financed by the Emilia-Romagna Region.

The registry is physically located at the Unit of Epidemiology of the Department of Public Health.

The staff is composed of an oncologist as director, three biologists as data collectors, one statistician and one healthcare planning administrator.

The purpose of the registry, since its founding in 2001, has been to collect cancer incidence and survival for the target population, to promote ‘ad hoc’ studies and to collaborate with studies organised by other institutions. These activities contribute both to producing scientific reports and publication and to improving cancer prevention and control in the province of Reggio Emilia.

The main sources of information are: the files of the two pathology services, hospital discharge records and death certificates. Site-specific cancer registry information (i.e. mesothelioma, melanoma, breast and cervix) is also used to improve the accuracy of RECR data.

At the end of each incidence year, data are checked using IARCcrgTools. Other checks are also performed to evaluate data completeness and validity (mortality incidence ratio, the proportions of DCO, cases with morphological confirmation, and unknown cases). When data have been processed, incidence trends are analysed.

Interpreting the results

Population-based breast and cervical cancer screening programmes might influence the incidence rates. It should also be underlined that increasing use of PSA testing most likely caused an artificial rise in the incidence of prostate cancer.

Use of the data

The registry publishes data periodically on incidence, mortality and survival. The RECR is involved in several in-house and collaborative studies. These cover many fields: from epidemiological studies to clinical research, public health surveillance and social inequality studies.

Source of population

Census 2001 and population estimates for 1998–2000 and 2002 (National Institute of Statistics, ISTAT).

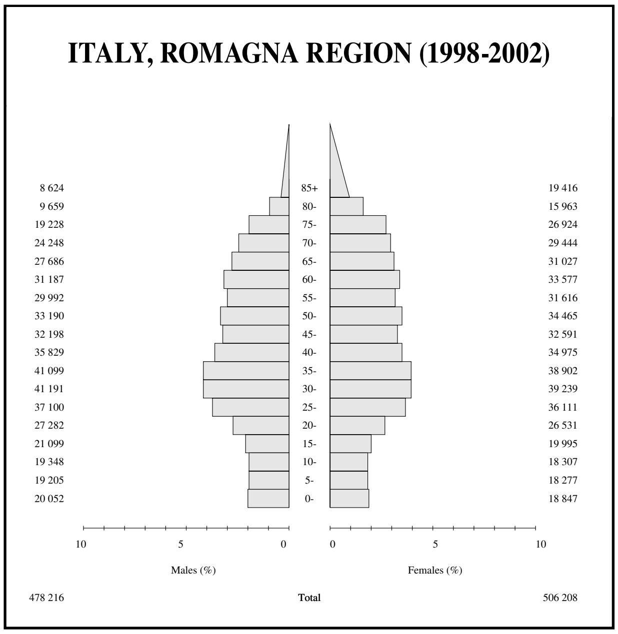
Multiple primary rules used

IACR rules (2004) on CI5 IX period.

Italy, Romagna Region

Registration area

The area covered by the Romagna Cancer Registry is part of the Emilia-Romagna region situated in the northeast of Italy. The Romagna region extends from the Adriatic Sea in the east to the borders of the provinces of Bologna in the west, Ferrara in the north, Florence and Pesaro in the south. The population is fairly stable. Among residents, the prevalence of non-Caucasians as well as of foreigners is low. The Romagna region amounts to 4769 km^2. The south of the region (48% of the total surface) is hilly and sparsely populated. The area is subdivided into three provinces (Ravenna, Forlì-Cesena and Rimini) with a total of 68 municipalities. The population density is 158/km^2 in the Province of Forlì-Cesena, 199/km^2 in the Province of Ravenna and 544/km^2 in the Province of Rimini. The area is socioeconomically homogeneous. The proportion of adults employed is 59.9–60.5% for men and 40.5–42.9% for women. The industrial and agricultural sectors employ 29.6% and 7.5% of the active population, respectively.



ITALY, ROMAGNA REGION (1998-2002)

Cancer care facilities

The Romagna region has 13 public (National Health Service) hospitals and 15 certified private hospitals. The total number of hospital beds is 5163 (or 5.2 per 1000 residents) with 221 821 annual discharges. The number of general practitioners is 836 (0.84 per 1000 adult residents). Cancer care facilities in the area include medical oncology departments and centres for early detection of cancer at the hospitals of Ravenna, Forlì, Faenza, Lugo, Cesena, Rimini and Riccione. The hospital-based oncology departments in the three provinces of Romagna (Forlì-Cesena, Ravenna and Rimini), offering a total of 168 beds (87 inpatient and 81 outpatient), have long been working towards a greater understanding of all aspects of the cancer problem, with the final aim of improving the quality of health care and patient management. The Cancer Institute of Romagna (*Istituto Scientifico Romagnolo per lo Studio e la Cura dei Tumori* [IRST]) has recently been established to further enhance the already high-quality health care for cancer patients of the region and to become a cancer centre of excellence for central Italy. Part of the institute's mission is to take in hand the fundamental research programmes and activities that the public health sector cannot cope with.

Registry structure and methods

The Romagna Cancer Registry was funded by the Istituto Oncologico Romagnolo until 1995, and has been supported by the Government of the Emilia-Romagna Region since 1995. The major information sources for the Romagna Cancer Registry are the archives of histology and cytology reports, hospital discharge forms, outpatient records of the medical oncology departments, the archives of private clinics, and death certificates obtained from the departments of public health of local health care districts. The registry is staffed by an epidemiologist, two statisticians, and 12 data managers.

Interpreting the results

Between 1996 and 1997, population-based screening programmes for breast cancer and cervical cancer were progressively implemented in each of the four health care districts of Romagna. In 2005, a screening programme for colorectal cancer was also launched.

Use of the data

Incidence data from the Romagna Cancer Registry are published through the IARC, the Health Department of the Emilia-Romagna Region, and the Italian Association of Cancer Registry (AIRTum). The registry participates in many research projects coordinated by the AIRTum. The active contribution of the registry to local cancer control strategies includes situation analyses (studies of the patterns of stage, diagnosis and treatment of major malignancies) as well as cervical and breast cancer screening monitoring. The registry database has been used for several cohort and case–control studies. Most of these have addressed the relationship between diet and digestive tumours, diet and breast cancer, pesticides and haematopoietic malignancies. Others have evaluated the risk of breast cancer for women bearing breast cysts and the risk of colorectal cancer for subjects undergoing polypectomy. The registry participates in the planning, conduct and analysis of numerous studies aimed at validation of diagnostic techniques and evaluation of health services.

Multiple primary rules used

IACR rules (2004) on CI5 IX period.

Italy, Salerno Province

Registration area

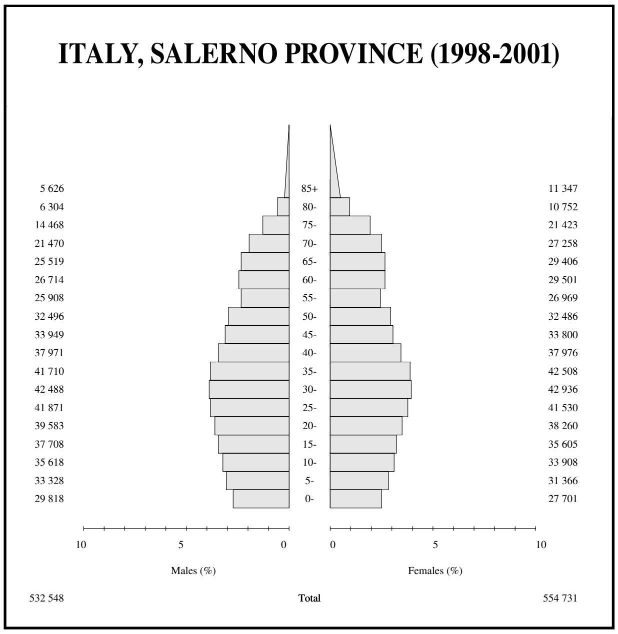
The Salerno Cancer Registry (SCR) covers the population of the whole Province of Salerno. It is the largest province in the Campania Region, consisting of 158 municipalities. The province of Salerno extends from the Tyrrhenian Sea in the west, to the borders of the provinces of Napoli and Avellino in the north and Potenza in the southeast. The vast area of Salerno has a varied territory, divided into inland hills (that cover 45% of its total area), mountains (29%) and coastal hills (15%), while only 11% is covered by plains.

Salerno is characterised by a densely populated urban area with a number of industrial activities in the north and by a wide rural area in the south. Coastal settlements and mountain villages are found in the west and in the east respectively.

Registry structure and methods

The registry is supported by the local administration (Provincia di Salerno) and is staffed by a Director, a data collection coordinator, an IT manager, two full-time registrars and five part-time workers.

Almost all sources of information (pathology reports, hospital discharge forms and death certificates) come from electronic media, but they are processed by registry personnel without any automated coding. Compared with the cancer registries of northern Italy, a higher proportion of patients are likely to be diagnosed and treated in hospitals located outside the province of Salerno. In order to assure the completeness of the data, the staff of SCR actively collects hospital discharges and pathology files from these hospitals.


ITALY, SALERNO PROVINCE (1998-2001)

A huge population data file allows us to prevent double registrations. Follow-up status is periodically updated, and this procedure consists of annual linkage with the mortality registry and by active research for vital status in the registry offices.

Interpreting the results

Incidence rates are influenced by a probable risk gradient between the urban north and the rural south. In the north some areas are also potentially affected by water pollution due to past industrial contaminations. A population-based screening programme for breast cancer was implemented only few years ago; we expect that it will affect breast cancer incidence and mortality rates only in the future.

Use of the data

Reports on incidence, mortality and survival are periodically provided by the Salerno Cancer Registry to general practitioners, public health professionals and epidemiologists. Specific and collaborative studies on survival, dietary and other risk factors are in progress.

Source of population

Census 2001 and population estimates for 1998–2000 (Istituto Nazionale di Statistica – ISTAT).

Multiple primary rules used

IACR rules (2004) on historical data.

Italy, Sassari Province

Registration area

The Sassari cancer registry covers the population of Sassari province in the Mediterranean island of Sardinia (Italy). The population at the most recent census (2001) was 453 628. Between 1991 and 2001 there was a small population decrease of about 0.3% (1276 persons); nevertheless in the previous decade there was an increase of about 4.5% (20 286 persons).

The province covers 7520 km^2 and has a population density of 60 persons/km^2, nearly 1/3 of the national population density. The population is not evenly distributed across the land; the provincial chief town has 128 000 inhabitants; three towns have 30 000–40 000 inhabitants, three towns have 10 000 inhabitants and all the other people live in 83 small villages.

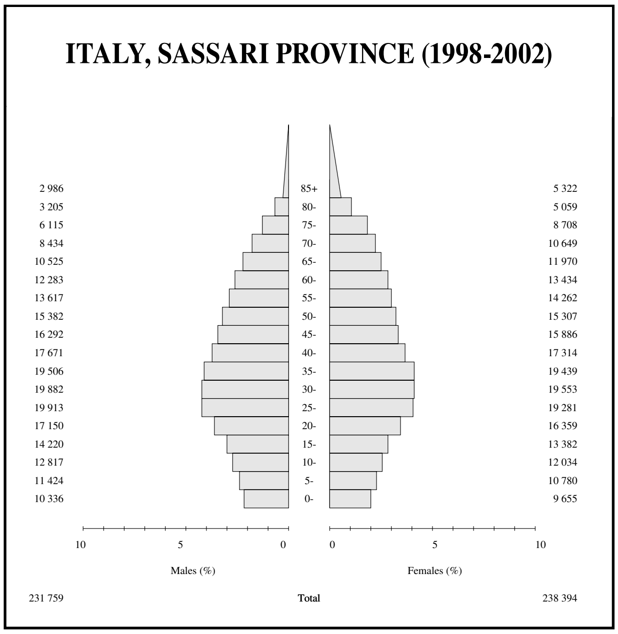
With few exceptions, the population is of the same race and the same culture. The economic activities are mostly agriculture and tourism. In the north of the area there are also two harbours for trade and one cracking plant.

Cancer care facilities

The National Health Service provides general health care through 1 regional and 4 district hospitals and primary health centres. Private practitioners supplement this.

The oncology department is located in the regional hospital in Sassari, and provides facilities for diagnosis, PSA testing as a routine procedure for elderly people, cancer surgery, and chemotherapy services.

Patients suspected to have cancer in the primary and secondary care facilities are mostly referred to district or regional hospitals. Usually patients are referred to district hospitals, but can also use hospitals in other provinces or outside of the island.



Registry structure and methods

The registry is a result of the work in partnership between the Epidemiology Service of Azienda Sanitaria of Sassari and the Anatomy and Histopathology Institute of Sassari University. It is funded by Azienda Sanitaria and is located in the Epidemiology Service. Four epidemiologists and two health workers staff the registry.

The registry collaborates in research with the institute of Anatomy and Histopathology Institute of Sassari University and the genetics OU of the CNR in order to define the prevalence of some genetic markers (BRCA, BRAF) and their influence on the prognosis of tumours.

The Sassari Cancer Registry (SCR) has collected, starting from 1 January 1992, all cases of malignant tumours occurring in the Sassari province. Particularly, all tumours listed in sections 140-208 of the ICD-9 and in sections C00–C97 of the ICD-10; intracranial and spinal neoplasms, malignant and benign; *in situ* carcinomas are normally collected but not utilised to calculate incidence, except urinary bladder carcinoma. The cases with insufficient detail are considered just when evidence is clear or when a tumour diagnosis is found on the death certificate.

The variables collected are: health unit to which patients belong, name, place and date of birth, sex, marital status, address, occupation or social class, attending physician, hospital and department of admission, site of tumour, presence of tumour in other family member, basis of diagnosis, grading, extension (or TNM) of neoplasm, leading treatment, causes of death, and place and date of death.

The registry receives the list of all persons admitted to Sassari Hospital and the list of biopsies. In addition, we use active casefinding in two regional hospitals (Sassari and Nuoro), in five district hospitals, in all medical offices for oncology and in the death registration offices.

Registry staff visit these sources periodically, and scrutinise the medical records of departments concerned with diagnosis and treatment of cancer, to identify and abstract information on cases of cancer, diagnosed by all methods, among residents of the registry area. Cancer is not a reportable disease, and the registry does not receive information about cancer cases from private practitioners. Arrangements have been made with the hospitals outside the region to notify the cancer cases in Sassari residents that are diagnosed or treated in their area.

In order to verify the completeness of the registry, the mortality/incidence ratio and DCO percentage are calculated annually, and the list is linked with that of the hospital's inpatient records and biopsies.

Interpreting the results

In the registry area, hospitals and diagnostic facilities are adequate in number and well distributed in the territory, so that it is unlikely that cases referred will be missed. Also, ASL operates a screening service for breast cancer and cervical cancer.

Use of the data

The registry prepares an annual report of cancer incidence highlighting changes and peculiar tumours (e.g. Kaposi sarcoma, chronic myeloid leukaemia, chronic lymphatic leukaemia), and points out the registered cancer cases survival after five years from registration.

The data of the registry have been used from the regional government to define cancer-control plans.

Source of population

1992–2002: Intercensal estimates (based on the 1991 and 2001 census data, making allowance for births, deaths and migration into and out of the province).

Multiple primary rules used

IACR rules (2004) on historical data.

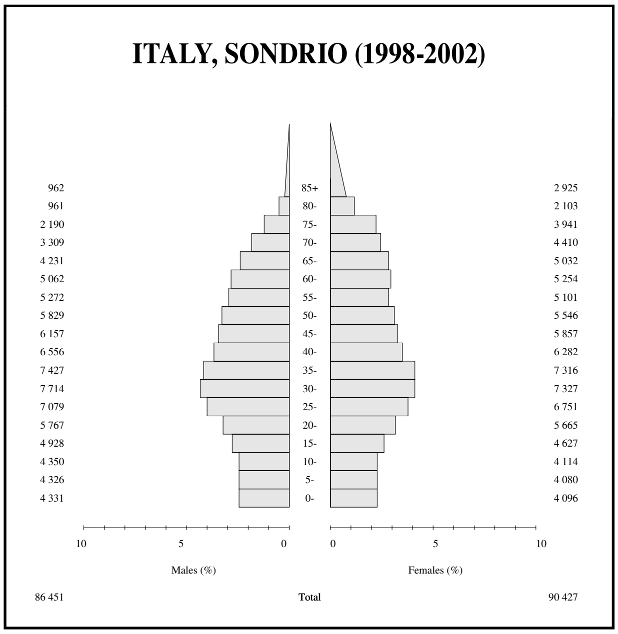
Italy, Sondrio

Registration area

The Sondrio Registry covers the population of the district of Sondrio in Northern Italy. It is a predominantly mountainous district, but about 68% of the population lives under 600m above sea level, 18% from 600–1000m and the remainder over 1000m. The main city is Sondrio, with 23 000 inhabitants. The greater part of the population lives in rural areas or small towns with <5000 inhabitants. The population is Caucasian (99.8%), and predominantly Christian. Women (51.1%) have longer life expectancy (median age of death for males is 74 years; for females, 84 years). In the district of Sondrio a small proportion of immigrants (1.4%) were registered in the national census of 2001.

Cancer care facilities

The public health services department, through 4 public hospitals and a network of primary health centres, provides general health care in the region. Hospitals provide cancer surgery, thoracic surgery, neurosurgery, haematology, radiotherapy and chemotherapy services and imaging services (4 CAT scan, 2 NMR). About 15% of patients with cancer are referred to secondary care in hospitals in Milano (120km distant).



Registry structure and methods

The registry is located within the Public Health Department, which provides physical and financial support. The registry is staffed by a full-time medical doctor (epidemiological specialist), a full-time nurse (registrar), and a part-time informatics specialist. The Istituto Nazionale per la cura dei Tumori of Milano (INT) provides technical and epidemiological support.

The registry receives all Italian Hospital Discharge Data of inhabitants in the area of the registry, databases of pathology laboratories in Sondrio and Milano area and mortality databases (pre-coded data). The registry scrutinises the records with cancer diagnosis or treatment and recodes all cancer cases. The staff scrutinises registers of radiotherapy and chemotherapy services and of hospitals when cases are uncertain.

If DCO (Death Certificate Only) cases are detected, the registry interviews the practitioner. Quality control, i.e. evaluation of DCO, of percentage of microscopically verified cases, of mortality/incidence ratio, of time trends, external comparison with Italian Registries, and capture-recapture analysis with independent databases (the Registry of Mesotheliomas, Italian Association of Paediatric Oncologists), are carried out with INT. The registry began the registration of incident cases in 1998 and has collected 6600 prevalent cases (with incidence date before 1998).

Interpreting the results

The population within the area is stable, and there have been no changes in the availability of diagnostic and treatment services or in definition and coding.

Screening for breast cancer by mammography has been active since 2000; screening for melanoma has been offered since 1999. The number of PSA tests is increasing; in 2004 there were 16 000. In the past many workers have been exposed to siliceous powder, and in 2004, the prevalence of silicosis was 800 cases.

Use of the data

The registry prepares an annual report of cancer incidence and survival. The data are used for evaluation of health services (for example migration of patients, terminal care). Some special studies on therapy for breast cancer have been carried out.

Source of population

Census 2001 and population estimates for 1998–2000 (National Institute of Statistics, ISTAT).

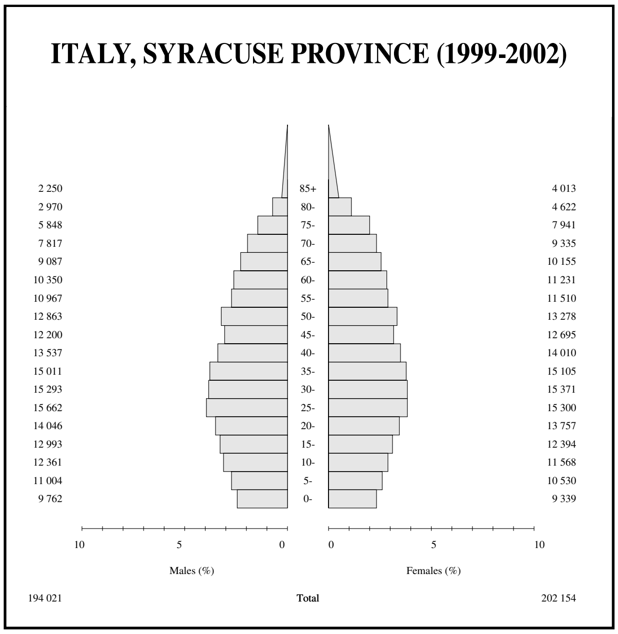
Multiple primary rules used

IACR rules (2004) on CI5 IX period.

Italy, Syracuse Province

Registration area

The Syracuse Cancer Registry inhabits the Territorial Registry of Pathology (RTP) of the Local Health Authority of Syracuse. The Registry covers 21 municipalities within the province of Syracuse in southeast Sicily. The area consists of a western highland with altitudes ranging from 450–865m, and an eastern coastal plan facing the Mediterranean Sea. The province borders the province of Catania in the north and the province of Ragusa in the south. The population density is 193 inhabitants/km^2. The province has about 400 000 inhabitants; the principal town, Syracuse, has about 123 000. People over age 65 comprise 15.5% of the population; those under age 14 comprise 17%. The area is socioeconomically heterogeneous, with an industrial economy in the cities of Augusta, Priolo and Melilli, and an agricultural economy in the north (District of Lentini) and south (District of Noto). The great majority of Syracuse's population is employed in tertiary activities, especially tourism. With a few exceptions, the population is of the same race and the same culture.



Cancer care facilities

In the area covered by RTP there is a main hospital (A.O. Umberto I) in Syracuse and four other public municipal hospitals (in Lentini, Augusta, Avola and Noto), five certified private hospitals and 396 general practitioners. The Syracuse and Avola hospitals have medical oncology units with chemotherapy services. There are no radiotherapy services. The province has few cancer care facilities; many patients are admitted to hospitals and specialised institutes outside the RTP area at the University of Catania. Many cases are diagnosed and treated in extra-regional hospitals with comprehensive cancer services (esp. in northern Italy).

Registry structure and methods

The registry is sited within and supported by the Healthcare District of Syracuse. RTP was established in 1997 by the Sicilian Government with the partnership of Department of Hygiene of the University of Catania and the Syracuse Local Health Authority. In 2005 it joined the new Integrated Cancer Registry (RTI) of the Province of Catania, Messina and Syracuse. Two full-time epidemiologists, one part-time epidemiologist, two full-time health nurses and one full-time registrar staff the registry, with MDs and undergraduates (epidemiologist and pathologist) of the University of Catania. RTP started on 1 January 1999, after a one-year experimental phase to evaluate feasibility and to collect prevalent cases. Registration is voluntary and based on active casefinding.

The major information sources for the Syracuse Cancer Registry are histology and cytology reports, the regional archive of hospital discharge forms, hospital clinical records, the archives of private clinics, clinical and administrative records of local healthcare districts, and death certificates obtained from the department of public health. The registry checks municipality rosters for vital status.

Since 1996 the Registry has received from the Regional Department of Epidemiological Observatory the records of all residents admitted to any regional or extra-regional hospital. Active casefinding is undertaken in hospitals, pathology laboratories, and local healthcare districts. The department of public health provides copies of death certificates for all causes. Arrangements have been made with hospitals outside the region to notify the Syracuse residents diagnosed and treated in their area. A traceback is performed for undefined malignity, unknown primary site, with outpatient record as the only source or other missing information as well as death certificate notifications. Traceback includes contacting the general practitioner and rescreening the sources.

Data collection and registration is done in three steps: a) checking data quality and linkage with the other information; b) evaluating and coding all cases by two epidemiologists; c) computer entry with IARC CanReg software. Follow-up procedures include periodic record linkage with mortality data. Specific procedures and keywords restrict file access.

Interpreting the results

The insufficient cancer care facilities and the number of cancer patients hospitalised outside the province create many problems for casefinding. Differential distribution of environmental and occupational exposure can lead to different incidence rates. In the registry area some suspected etiological factors have been investigated. Chemical industries in Augusta, for example, represent the main source of water and air pollution that influence the high incidence rates of several tumours, especially of lung cancer.

Since 2001 there have been population-based screening programmes for breast cancer and cervical cancer in Syracuse city (although breast cancer screening was interrupted in 2004). PSA testing is commonly used as a diagnostic technique, but not in organised screening programmes.

Use of the data

The Registry aims to identify cancer incidence in an area (southern Italy) formerly covered only by the Ragusa Cancer Registry, that has low incidence rates, probably related to Mediterranean dietary habits and lifestyle. The registry seeks to establish these incidence rates to evaluate future needs and to target prevention activities appropriately. The registry contributes to local cancer control strategies via monitoring cervical cancer screening and evaluating health services. The registry prepares an annual report of cancer mortality and, more recently, of incidence as well. The Registry is not currently involved in national or international epidemiological research, but data are provided to the Local Health Unit and the Regional Government for planning health services. Survival studies will be possible after five years of recording.

Source of population
Source of population is the 2001 census, taking into account birth, deaths and migration, produced by the National institute of Statistics (ISTAT).

Multiple primary rules used
IACR rules (2004) on CI5 IX period.

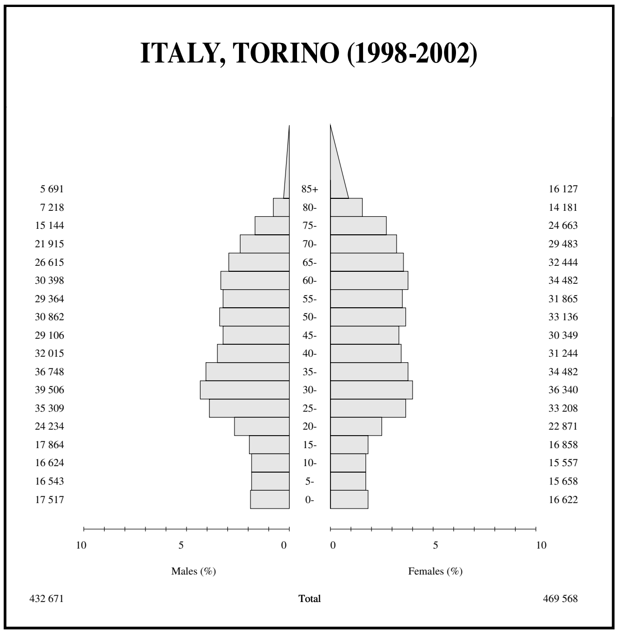
Italy, Torino

Registration area

The area covered by the Piedmont Cancer Registry corresponds to the city of Torino, which is the main city of the Piedmont Region, in the northwest of Italy. At the year 2001 census the population was 902 235 inhabitants. The present population structure is still influenced by significant internal migration: 4.4% of the population was born in the northeast of Italy, 4.5% in the centre and 26.6 in the south. This composition may influence incidence figures, as people born in southern Italy have lower risk profiles than people born in northern regions.

Cancer care facilities

In Turin and its surroundings there are 14 public hospitals and 12 private clinics: all these hospitals and clinics offer cancer treatments in varying proportions. Recently the Piedmont Region has developed a regional network for cancer services with four sub-areas serving the city of Turin. Since 1992, two screening programmes have been set up in the Turin area: mammographic screening for women aged 50–69 years and cytological screening for women 25–64 years of age. In 1998 a screening program for colon cancer was implemented, based on sigmoidoscopy for men and women aged 58 years or faecal occult blood test for men and women between 59 and 69 who refused the sigmoidoscopy.



ITALY, TORINO (1998-2002)

Registry structure and methods

The Registry is a part of Centre for Cancer Prevention (CPO). The registry is staffed by a director, two epidemiologists, two full time registrars and six part-time registrars. Sources of information and methods of registration remained unchanged in recent years.

The principal sources of information for the Registry are: a) the hospital archive of clinical records; b) the regional archive of hospital discharge forms; c) pathology reports; d) the archives of Day Hospitals and Radiotherapy Services; e) health insurance files for those cases treated outside the region; and f) death certificates. The Registry has access to the municipality roster in order to check personal data for vital status. Registration is carried out in an almost completely active manner. The collection of data comes about in two steps: a) a provisional input into a portable computer, carried out at hospital archives after reading clinical records and histological reports; b) a definitive input, after checks for data quality and linkage with other information. Follow-up procedures include periodical record linkage with the mortality Registry and the active follow-up in the municipality rosters.

Interpreting the results

During recent years, the incidence trend slowed its increase. Tobacco- and alcohol-related cancers are clearly decreasing in both sexes, with the only exception being lung cancer in women.

Breast, colorectal and prostate cancers are increasing, mainly due to the screening programs (for breast and colon) or the increasing use of opportunistic PSA testing.

For more than a century, Torino has been the Italian capital of automotive industry (cars, trains, trucks, planes). In recent decades, automation of the production processes had importantly cut the proportion of manpower, as well as had improved the working conditions and put occupational hazards under strict control. However, due to the latency of cancer induction, a consistent occupational etiological fraction is still present in the Turin cancer incidence of mesothelioma, lung and bladder cancers. Furthermore, this heavy industrial environment, together with road traffic, has also induced significant air pollution, responsible for a further fraction of respiratory cancers.

Use of the data

The registry provides periodical reports on cancer incidence, prevalence, mortality and survival, published and updated on the web (www.cpo.it). The data are used by local heath authorities for planning for the regional network of cancer services. The data are also sent to the Italian Cancer Registries Association database. The Torino branch of the EPIC cohort study is annually linked with the Piedmont Cancer Registry in order to check the occurrence of cancers. A follow-up facility is also provided on demand for clinical epidemiological studies.

Source of population

Municipality rosters (balance of resident population recorded by the municipality roster at the end of each year).

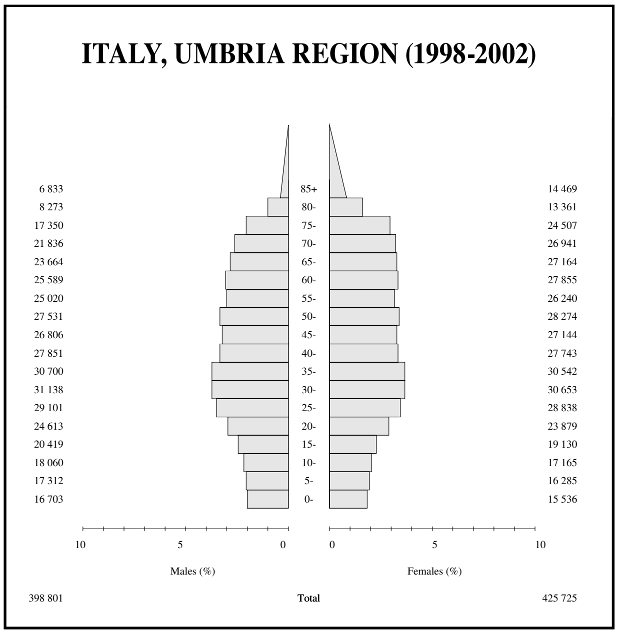
Multiple primary rules used

IACR rules (2004) on historical data.

Italy, Umbria Region

Registration area

The Umbrian population-based Cancer Registry covers the population of the Umbria Region. Umbria is a small Region in central Italy, divided into two Provinces. The regional population was 825 826 inhabitants (426 664 females) at the last census (2001). The region's area is 8456 km^2, and population density is about 96 inhabitants per km^2. The population is older than the Italian average: the ratio of people >65 years old to all residents is over 23%. The population is stable, growing slowly due to migration while natural balance is negative. Foreigners, most of them coming from Eastern Europe and North Africa, form about 2% of the resident population. Nearly 70% of people live in centres of >5000 inhabitants. The great majority of Umbria's population is employed in services and industry (agriculture 6% both sexes). The unemployment rate is at 8.9%.



Cancer care facilities

Health care is provided mostly in public hospitals and districts of the 4 Local Health Services. There are 2 main teaching hospitals and 18 public hospitals in the region with 3949 beds overall, as well as 5 private clinics.

The main specialised oncology centres (including clinical oncology, surgical oncology, paediatric oncology, radiotherapy and haematology specialties) are located in the two larger cities, Perugia and Terni (maximum distance within the region 55km). As an overall technology investment indicator 18 TC, 7 RMN, and 2 PET are available in the regional centres (data from Osservatorio Regionale Tecnologie).

Registry structure and methods

The Cancer Registry is managed at the Department of Hygiene of the University of Perugia. The registry is funded by the Regional Health Authority while staff and equipment are supplied by the University. All the staff is yet part-time. Sources used for casefinding include public and private clinics/hospitals outpatient records, pathology reports, radiotherapy outpatient records, and death certificates.

Relevant information for eligible cases (i.e. residents) is abstracted from medical records of 20 public and 5 private hospitals. Other sources of data are cytology centres for cervical cancer screening, personal case histories and independent studies, reimbursement requests for patient treated outside the region, and other cancer registries.

A traceback is performed for cases of undefined malignity, of unknown primary site, with outpatient record as the only source or with other missing information besides death certificate incident cases. The traceback procedure includes contacting the family doctor and re-abstracting or re-screening of acquired sources.

Interpreting the results

Opportunistic screening for cervical cancer was introduced long ago. More recently, the opportunistic screening was supplanted by an organised programme, and an organised screening programme for beast cancer was also introduced (1999). Opportunistic screening activities for prostate cancer and melanoma do exist, but are perhaps less widespread than in most other northern Italian regions. Invitation letters for the first round of the large bowel screening program are now being distributed. Historically, there has been an area of high risk for gastric cancer in the north of the region.

Use of the data

Annual incidence and survival reports are produced and distributed. A survival study by prognostic factor for breast and large bowel cancer is ongoing. The registry participates in various multicenter researches (e.g. the EUROCARE study on patient survival, the OCCAM study on occupational cancer monitoring, and the IMPACT study on breast cancer screening effectiveness). Policymakers also use registry data for planning and evaluation of health services.

Source of population

Census 2001 and population estimates for 1998–2000 and 2002 (ISTAT).

Multiple primary rules used

IACR rules based on ICD–O–1.

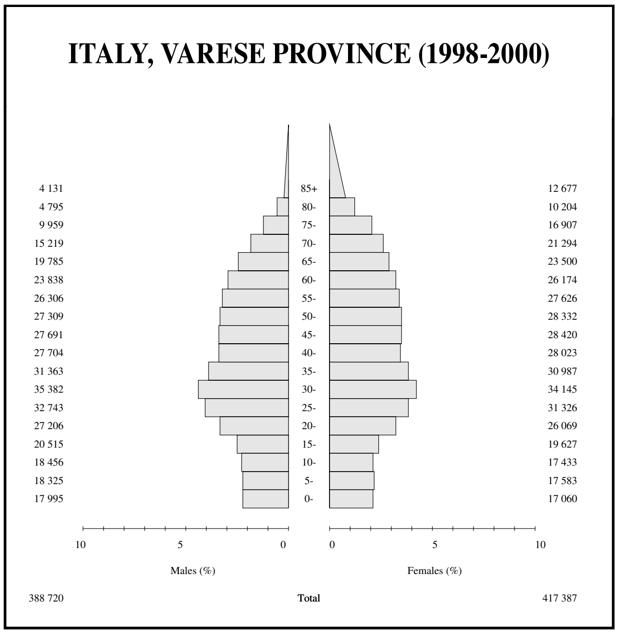
Italy, Varese Province

Registration area

The Province of Varese is in northern Italy. It is bordered to the north by Switzerland, to the west by Lake Verbano and the river Ticino, which mark the border with the Region of Piedmont, and to south and east by two other Provinces of the Region of Lombardy, to which Varese Province also belongs. The northern part of the Province is mountainous; the southern part encompasses part of the Lombardy plain and is flat. The Province has an area of 1198 km^2.

The population has increased considerably since the 1960s (581 526 in 1961; 807 579 in 2000). In these years considerable numbers of people have moved into the Province from eastern and southern Italy. Those who settled tended to retain the distinctive dietary and cultural habits of their origins, which differ considerably from those of the indigenous population. These differences have made it possible to conduct descriptive studies on differences in cancer risk by place of birth and also to perform analytical studies on diet and cancer.

The population density is 695.6 inhabitants per km^2. The ratio of elderly to children (over 64 years/less than 15 years) was 132.8 in 2000. Currently about 43% of the working population are employed in industry—a considerable decline compared to 1971—and about 2% are employed in agriculture; it is not possible to partition the Province into urban and rural areas.


ITALY, VARESE PROVINCE (1998-2000)

Cancer care facilities

The Province of Varese is served by 11 general hospitals, including one university teaching hospital with modern facilities for the diagnosis and treatment of cancer. There are also five private clinics. There are 3950 hospital beds; the hospitalization rate is 161/1000 per year.

Registry structure and methods

The Lombardy Cancer Registry, which serves the Province of Varese, was established in 1974; is it now called the Varese Cancer Registry. The Registry is supported by the Lombardy Regional Health Authority and is run by the Cancer Registry and Environmental Epidemiology Unit of the Milan National Cancer Institute. The professional registry staff consists of three epidemiologists, two data managers/statisticians, three case ascertainers and three clerks concerned with record linkage and the checking of data.

The Varese Cancer Registry uses an automated cancer registration system, called Open Registry (Methods of Information in Medicine 2005;44:66-71) developed in-house and based on the Linux operating system and Oracle database. The main electronic information sources are *hospital discharges*, routinely generated by all hospitals in Italy; *surgical pathology reports* from pathology units in the Province and, since 1998, from major pathology units outside the Province, which often examine specimens from persons resident in the Province; and *mortality data* from Local Health Units. Using the Open Registry software and translation tables to cope with the different information coding systems in use, 60% of cases are identified and accepted automatically. For the remaining cases, the clinical records are scrutinised manually. The accuracy of the automated system has been tested by comparison with manual registration and showed a site code concordance between the two systems (automated and manual) of 98.4%. In collaboration with Local Health Units of the Lombardy Provinces of Brescia, Mantova and Sondrio of the Lombardy Region, Open Registry has been exported to the Cancer Registries of these Provinces. The completeness of registration is monitored yearly using capture-recapture methods. Clinical consistency is also checked routinely by re-abstraction and manual recoding of a random sample of cases.

The Varese Cancer Registry participates in major epidemiological studies, including those of EUROCARE, ORDET, EPIC and ACCIS.

Source of population

Estimates (ISTAT http://www.istat.it).

Multiple primary rules used

IACR rules (2004) on CI5 IX period.

Italy, Veneto Region

Registration area

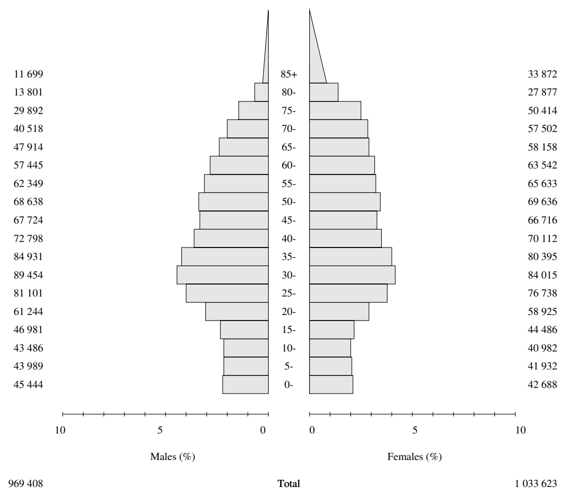
The Veneto Region is the largest region in Northeast Italy, with 4 527 694 inhabitants at the 2001 Census, 44% of whom (2 002 705 inhabitants) reside in the area covered by the Veneto Tumour Registry, which includes six of the seven major urban centres and almost all the mountainous part of the Region.

Immigrants make up 6% of the population covered by the Veneto Tumour Registry (source: Ministry of the Interior). Most of these come from Eastern Europe (47.8%) and from Africa (16.7% from Maghreb and 11% from other Countries); 15% are from Asia (including China).

Most Venetians are Christian Catholics, whereas half of immigrants embrace Christian religions (25% Orthodox Church, 17% Catholic, and 4% Protestant); a third of the foreign population is Muslim.

The Region encompasses many of the leading economic districts in Italy: the unemployment rate in 2001 was only 4.1%, compared to the national average of 11.6%.

At the 2001 Census, employment was distributed as follows: 4% in agriculture, 42% in industry and 54% in other activities (national averages are 5%, 34% and 61%, respectively): industrial activities are distributed throughout the territory rather than being geographically concentrated.


ITALY, VENETO REGION (1998-2001)

Cancer care facilities

Twenty-one Local Health Units (LHU) are responsible for all public health-related matters, including the management of all the hospitals in the Region (98 in the year 2000). Only the two major hospitals are managed autonomously. Most of the LHUs provide comprehensive services for cancer diagnosis, surgery and chemotherapy: radiotherapy and a few expensive diagnostic tools are available at least at county level (the Region includes seven counties), while patients with rare cancers or particular sites involved (i.e. brain tumours) are mostly referred to a restricted number of departments. Paediatric patients are treated in the two major hospitals.

Registry structure and methods

The Registry is financially supported by the Regional administration. The staff is composed of a physician (director of the registry), three registry operators, three statisticians, a data manager, two computer programmers and two clerks with secretarial and data-entry duties.

The registration system uses medical information, received annually from the following computerised and codified sources:

1. Hospital discharge records from all the hospitals in the region, transmitted by the Regional Department of Social Security and Health;
2. Death certificates relating to all deaths among residents in the region, transmitted by the same Department; and
3. Pathology records transmitted by the fifteen pathology laboratories covering the registered areas.

Furthermore, all the LHUs of the region transmit a copy of the population files, which are merged into a single archive, used as a reference for linking source records: the latter are evaluated using a case resolution programme that accepts: cancer cases where data from two or more sources are identical; histologically confirmed cases in the presence of other compatible hospital diagnoses (e.g. metastases or ill-defined sites); and histologically confirmed skin cancer unless combined with skin melanoma.

The programme rejects diagnoses based on only one source (unless based on histology), multiple primary tumours and discordant or incompatible diagnoses: in these situations manual checking is carried out by the registry operators, who where necessary gather further information from the local information systems of the LHUs and clinical records from the hospitals.

A quality assessment of automatically accepted cases was carried out by a re-abstraction study in the year 2002, with positive results, and a few corrections were consequently made to the programme.

Interpreting the results

The proportion of aged population has markedly increased: ageing index for the whole region, which was 107 in 1991, had become 136 in 2001; in the area covered by the registry it rose from 119 to 145.

A prevention programme for early detection of skin melanoma has existed since 1990. Organised screening for breast and cervix cancer detection started in 1998 in three and five LHUs, respectively, and progressively included further LHUs. PSA testing became a routine practice in the late 1990s.

Use of the data

Incidence figures with LHU details are reported on the Registry website, as well as prevalence and survival figures for the entire Registry area: a report has also been prepared and some small area analyses of incidence and mortality have been carried out.

The Registry collaborates with all other Italian Registries in research projects and publications of incidence, prevalence and survival data.

The Veneto Tumour Registry is currently involved in epidemiological researche (EUROCARE IV, Concord, Haematocare, ACCIS, Eurocim, and others).

Veneto Tumour Registry's data are used for drafting the Oncological Regional Health Plan of the Veneto Region.

Source of population

1997–2000: Municipal registries estimates of population at 31st December (source: National Institute of Statistics, ISTAT). 2001: census, National Institute of Statistics, ISTAT. 2002: Municipal registries estimates of population at 31st December (source: National Institute of Statistics, ISTAT).

Multiple primary rules used

IACR rules (2004) on historical data

Latvia

Cancer care facilities

The Latvian Oncology Centre, 2 regional oncology hospitals and the oncology department at the Republics Clinical Hospital provide complete specialized diagnostic and treatment services for the population of Latvia. All of these hospitals have well-equipped radiology departments. Specialised aid for children is provided by the oncology department of the Central Children's Hospital.

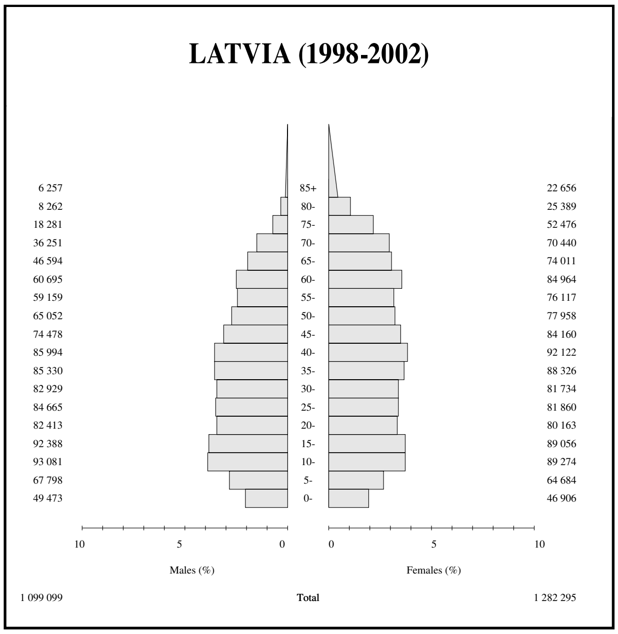
Registry structure and methods

The staff of Latvian Cancer Registry (LCR) includes 5 officials: an MD medical statistician, an epidemiologist (biologist), a programmer, a PC operator and the principal of CR (director).

All physicians and practitioners (GP, out-patient department, hospital, pathology and forensic medicine laboratory) have to report new cancer cases to LCR. At least quarterly the persons responsible for oncology at every district central hospital in the republic provide information on cancer in their districts (new cases, deaths, changes of therapy, progress of the disease, etc.).

Additionally, the LCR receives regular information from the Latvian Agency for Medical Statistics concerning the cases identified from death certificates.

The completeness of the data is evaluated by comparison of the CR data with the data of big hospitals. A specific evaluation study is not performed.



Registration area

Since 1965, the cancer registry has covered all the population of the republic, but a separate cancer registry unit (LCR) was organised in 1993, after state independence was re-established. The area covered has not changed, but the population has changed considerably: in 1966–1967 mainly because of the departure of Soviet Army troops and their families; during the reporting period (1998–2002) about 29 000 of the population were lost because of emigration; but mainly—about 71 000—because of the natural decrease in the population (about 14 000 persons per year).

Interpreting the results

The availability of medical services is nearly the same over time, with some difficulties for the less-secure population, but cancer diagnosis and treatment possibilities have increased.

From the beginning of the registry the ICD-7,8,9 revisions were used for coding of malignancies. Now all data are transformed to ICD-10 (topography) and ICD-0 (morphology) codes.

No organised screening programmes have been organised in Latvia, but opportunistic programmes for breast cancer (mammography) and cervical carcinoma (Pap smears) as well as PSA tests are ongoing.

Use of the data

The LCR publishes regular statistical issues. During the 1998–2002 period: *Cancer Incidence in Latvia 1997–1998* (the 4th issue) and *1999–2000* (5th issue); *Cancer Mortality in Latvia, 1980–2000* (2002) and *Cancer Incidence and Mortality in Latvia, 2001–2002* in 2004.

The LCR is not currently involved in epidemiological research, but some projects have been completed recently. The CR data are widely requested and used by policy makers, insurance companies, etc.

Source of population

1998–1999 Central Statistical Bureau of Latvia (estimation allowing for the birth/death levels and migration. Census 2000 (March 31, 2000): Provisional results of the 2000 population census – Statistical bulletin, Riga, 2001, 62p. 2001–2002: Estimated data from the Central Statistical bureau of Latvia.

Multiple primary rules used

IACR rules (2004) on CI5 IX period.

Lithuania

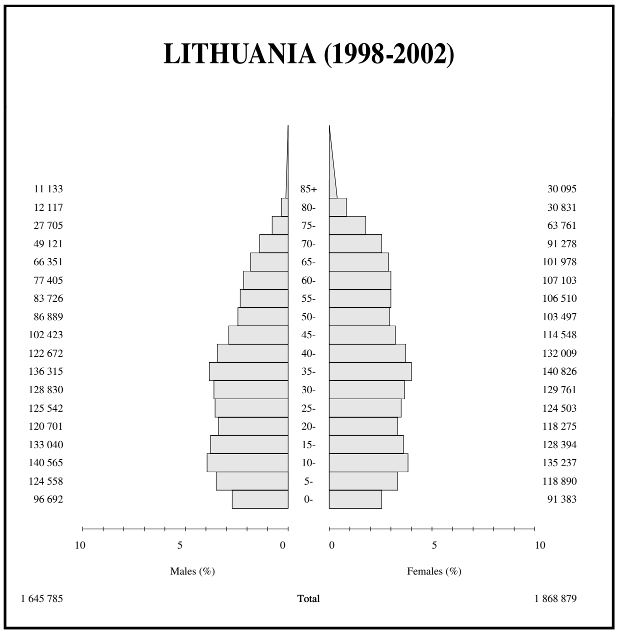
Registration area

Lithuania is the southernmost of the Baltic States, which were part of the USSR from 1940 through 1990. In 1990, Lithuania gained independence. Lithuania has total land area of 653000 km^2 giving a population density of 53.68 persons per km^2. The resident population in Lithuania in 2001 was 3 483 972 – 1 629 148 males and 1 854 824 females (census data) where 83.45% of inhabitants are Lithuanians, 6.74% Polish, 6.31% Russians, and 3.5% others. Birth rate in Lithuania has been decreasing for the last decade, and it continues to fall. In 2000, the crude birth rate was 8.52 per 1000 population. Average annual rate of natural increase was –1.3%. The infant mortality was 8.52 per 1000 live births.

Cancer care facilities

There were 97.9 hospital beds and 40.3 medical doctors per 100 000 population in 2000. The availability of diagnostic and treatment services is increasing. Modern complex treatment of oncology patients (surgery, radiotherapy, chemotherapy) is provided at Institute of Oncology Vilnius University, Kaunas Medical University Clinics, Klaipeda City Hospital and Siauliai City Hospital. Surgery and chemotherapy are also available at other university hospitals and major treatment centres.

The highly centralised healthcare system has been finally changed to a state insurance-based system in 1997. The changes required the registry to establish new connections with primary healthcare centres (360 in 2006) that became to play a major role in primary cancer assessment and referral of patients to diagnostic services.



Registry structure and methods

The cancer registry operates as a separate department of Institute of Oncology, Vilnius University. The registry staff includes 10 employees: epidemiologist, medical doctor, medical coders, programmer and registry clerks. Support to the registry is provided by the Institute of oncology. The principal sources of information on cancer cases are primary, secondary and tertiary healthcare institutions that are required to complete a notification when cancer is diagnosed.

Lithuania has a compulsory nationwide cancer registration since 1957. Administratively Lithuania was divided to 44 districts (“municipalities”) up to the year 2000. The new administrative division is built upon 60 municipalities established within the borders of previous territory units. Some of districts were split in two or three municipalities; some small territories were joined across borders. The cancer registry successfully adopted the new territorial division without loss of information on long-term trends within major units.

The compulsory case notification includes surname, name, sex, date of birth, place of residence, nationality, date of diagnosis, site according to ICD-9 from 1978 through 1997 and according to ICD-10 since 1997, morphology according to ICD-O-2 edition since 1993 and ICD-O-3 since 2003. Before 1993, a local one-digit morphology code was used. The cancer registry file is updated monthly with information on death certificates that are completed according to the international standards. The last update for the analyses presented here was done on 31 March 2005. On average, two notifications from different sources per skin melanoma case were registered since 2000.

There are obstacles to continuing the full-scale activity of the cancer registry due to legislative issues. The first regulations of the registry were signed by the Ministry of Heath in 1984. Discussion continued on cancer registry regulations despite the law on the registries adopted by the Lithuanian Parliament in 1996. The importance of the registry data was recognised by researchers, health care organisers and policymakers. The cancer registry data was used as a basis for the National Cancer Control programme adopted by the government in 2003, establishing cervical and breast cancer screening programmes and numerous local investment projects funded by EU and local sources.

Interpreting the results

During 1998–2002 there were no nation-wide cancer screening programmes. Some small-scale opportunistic activities were established for cervical, breast or colon cancer. PSA testing became widely available around 2000. The cervical cancer screening programme with a 3-year invitation interval started in June 2004. The mammography screening programme started in May 2006 though it is still lacking coverage due to limited mammography services. Despite the opposition of the experts, lobbying activities forced the introduction of nationwide free PSA testing in 2006. The registry is responsible for evaluating the effectiveness of these cancer screening programmes.

Use of the data

Annual registry reports on cancer incidence, extent of disease, microscopic verification of cases, mortality, and prevalence by site and municipality have been published since 1994. Registry publications covering incidence and mortality trends and survival data have been published on some individual sites. The registry is also involved in cancer epidemiology research, and has participated in several descriptive and occupational epidemiology projects including Chernobyl clean-up workers, nuclear workers, radiologists, and asbestos-, cement- and wood dust-exposed workers. The occupational exposure pattern in Lithuania follows that in industrial countries; study of environmental radiation exposure due to Chernobyl is needed in order to evaluate the consequences for the general population. A study of clean-up workers from Lithuania shows no elevated cancer risk.

Multiple primary rules used

IACR rules (1990).

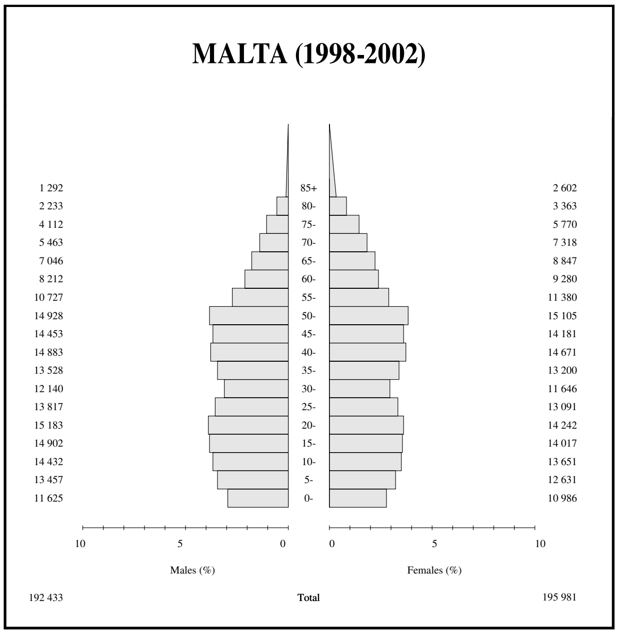
Malta

Registration area

The Malta National Cancer Registry covers the population of the Maltese Islands, a small archipelago in the middle of the Mediterranean Sea. The total resident population at the most recent census (2005) was 404 039.

There is no clear distinction on the islands between urban and rural areas. However the harbour area (centred around the capital Valletta) can be considered as the most urban, with much of the rest of Malta being suburban, and most of the northwest part and the whole of Gozo being rural.

The majority of the local population are Roman Catholic. The number of foreigners resident on the Islands is increasing, leading to growing changes in the ethnic compositions of the resident population. The Maltese people are descendents of ancient Carthaginians and Phoenicians, with strong Greco-Roman and Arab influences. European elements, namely Italian, Spanish and French with traces of Anglo-Saxon origins, were assimilated later.



Cancer care facilities

In Malta, there is a comprehensive national health service that is available to all Maltese residents and entirely free at the point of delivery. All residents have access to preventive, diagnostic, therapeutic and rehabilitative services in the Government Health Centres and Hospitals. The public health services are funded from general taxation. There is one major general acute hospital in Malta, a smaller one in Gozo and a number of public health centres scattered all over the islands. Since 1996, three private hospitals have also been operating in Malta. Cancer surgery is carried out in any of the above-mentioned hospitals, whilst radiotherapy and most of the chemotherapy are given at the oncology department in Sir Paul Boffa Hospital, which is the only cancer centre in Malta.

Registry structure and methods

The registry is located near to the major general acute (St. Luke's) hospital in Malta. It is part of the Department of Health Information within the Health Division and is wholly funded by the Government of Malta. A full-time principal medical officer, one full-time and one part-time registrar staff the registry.

The Malta National Cancer Registry uses both active and passive methods from multiple sources for data collection. Active data collection includes review of and extraction from the pathology laboratories' reports databases (histology, cytology and autopsy reports) of cases of cancer, review of the hospital files of known cases and collection of information from the National Mortality Registry (both active and passive). Passive methods include the receipt of notifications of cancer from the clinicians, a monthly report from the Oncology department on the new cases referred to their department and an annual report on the cases of cancer sent abroad for treatment by the state.

The National Mortality Registry is also housed within the Department of Health Information, and linkage between the cancer and mortality databases is routinely performed. The mortality registry is the recognised national source on death statistics.

Interpreting the results

It is estimated that only a small proportion of the cancers diagnosed in Maltese residents remain unregistered. These mainly include cases diagnosed, treated and followed-up abroad. The registry staff actively tries to reduce the proportion of cases that remain registered on the basis of a death certificate only by reviewing all possible medical information on the cases. The staff is permitted access to the hospital files of cases diagnosed and treated at all public and private hospitals and clinics.

To date, no organised cancer screening programme has been implemented in Malta. However, facilities for opportunistic screening for breast, cervical, prostate and colorectal cancers are available locally.

Use of the data

The registry has published cancer incidence and mortality information since 1992. On the registry's web site (http://www.sahha.gov.mt/pages.aspx?page=91) there are files with cancer incidence and mortality data for Maltese residents from 1994–2005/6 as well as other cancer statistics including survival and temporal trends. The registry is the recognised national source of information on cancer incidence. Its staff annually answers several requests for information originating from various sources, including both local and foreign clinicians and other professionals, students, journalists and interested organisations.

Source of population

1998–2002: Post–censal estimates. Census data with addition of births and immigrants and deletion of deaths and emigrants.

Multiple primary rules used

IACR rules (1990).

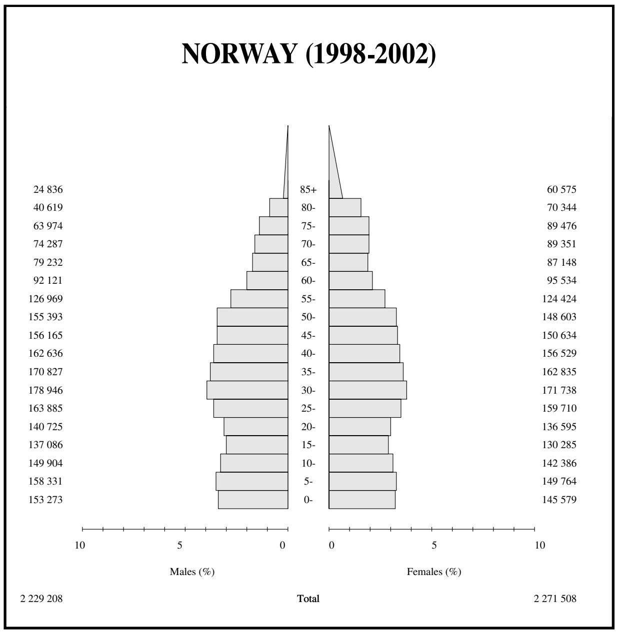
Norway

Registration area

Norway covers 324 000 km^2 between latitudes 57° and 71° N and longitudes 4° and 31° E. The total population is 4 640 219 (1 January 2006), most of whom are Caucasians, but 0.5% are Lapps and 8% are foreign-born (2% western and 6% non-western). At the 2005 census the main occupations for men were: industry 32%, agriculture 5%, community 22% and other services 41%; the corresponding figures for women were: industry 1.5%, agriculture 8%, community 57% and other services 33%.

Cancer care facilities

In 2004 there were approximately 4 hospital beds and 3.5 physicians per 1000 inhabitants. Surgical treatment of cancer is carried out both in general hospitals and at oncological centres. There are about 90 hospitals (both private and public) and a number of private clinics offering diagnostics and treatment of cancer in Norway. Most cancer diagnosis and treatment is, however, carried out at the public hospitals. These hospitals are organised in regions covering different parts of Norway (Eastern Norway Regional Health Authority, Southern Norway Regional Health Authority, Western Norway Regional Health Authority, Central Norway Regional Health Authority and Northern Norway Regional Health Authority). There are 10 radiotherapy departments in Norway, situated at different parts of the country.



Registry structure and methods

The Cancer Registry of Norway was initiated by the Norwegian Cancer Society and established in 1951. Since 1979 the Ministry of Health and Social Affairs has been administratively and financially responsible for the registry.

There are 130 employees in the Norwegian Cancer Registry. The Cancer Registry is organised in 4 departments: an administration (29 employees, including 9 information and 13 IT-staff) and three research departments (environmental and occupational research, screening research and clinical research). The staff consists of, among others, doctors, scientists, statisticians, research assistants, IT staff, economy, personnel and PR.

Site and morphology have been coded according to ICD-O-2 since 1993. Before 1993, site was coded according to ICD-7, while the morphology was coded according to a modified version of SNOMED. Primary tumours in different organs in one individual are classified as independent tumours. If multiple tumours occur within paired organs or other sites within the same ICD code (e.g. kidney, colon), the case is classified in such a way that it can be counted either as one primary cancer only or as the number of primaries that actually exists. For the female breast, two primary cancers may be registered in one individual. A double coding system is also used for lymphomas. Lymphomas in, for instance, the tonsils or the stomach are coded both to the lymphoma site and to the specific organ site.

The registry is based on compulsory reporting of all new cases of cancer in the Norwegian population since 1953. Each year the registry receives more than 100 000 reports which include clinical forms, copies of cytology, biopsy and autopsy reports, and copies of death certificates from Statistics Norway. In recent years the Patient Administrative System has been linked to the Cancer Registry of Norway to ensure completeness and quality. The registry is organised as a multi-user online database. All reports are interpreted and, after coding, updated and processed. At regular intervals, the registry material is matched against all deaths in the country and date and cause of death are recorded. Since the 1960 census, all inhabitants in Norway have had a unique personal identification number, and this number is used to link records from the different data sources.

Interpreting the results

The Norwegian Cancer Registry has both a cervical screening programme and a breast screening programme. PSA testing has become increasingly more common since the first commercial PSA test became available in 1989, and is now very common in the Norwegian population.

Use of the data

The purpose of the Cancer Registry is to:

- collect and, within the scope of the Regulations, process data relating to cases of cancer and cancer studies in Norway in order to document the distribution of cancer in the country and describe changes over time;
- conduct, promote and provide a basis for research to develop new knowledge of the causes, diagnosis, natural course and effects of treatment of cancer in order to improve and enhance the quality of preventive measures and medical assistance that are offered or provided to combat cancer, including the follow-up of individual patients and groups of patients;
- provide advice and counselling on medical assistance to combat cancer; and
- provide advice and information to other public administrative bodies and the population at large on measures that may prevent the development of cancer.

In addition to such purposes data in the Cancer Registry may be processed for the following purposes: management, planning and quality assurance of public health services and the public health administration, for the preparation of statistics and for research.

Main research areas are etiological screening-based and clinical, based on population data and epidemiological methods.

Multiple primary rules used

IACR rules (2004) on historical data.

Poland, Cracow

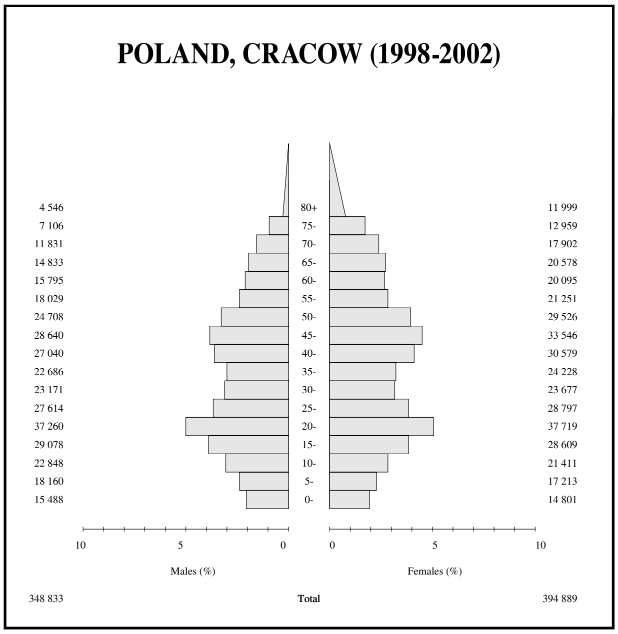
Registration area

The Cracow Cancer Registry covers the population of the Małopolska Province in southern Poland, an area of 15 144 km^2, with 3 233 799 inhabitants.

In 2000 the City of Cracow, the data for which are presented here, an area 327 km^2, had 741 500 inhabitants (46.8% male, 53.2% female). The population is little differentiated ethnically, and the large majority is Roman Catholic. The city of Cracow is one of the biggest industrial (with metallurgical, electromechanical, chemical and food industries), cultural and educational centres of Poland.

Cancer care facilities

In Cracow, diagnostic and treatment services for cancer are provided by the Centre of Oncology Maria Skłodowska-Curie Memorial Institute (220-bed hospital and an out-patient department for 300 patients daily) as well as 22 clinics of Collegium Medicum Jagiellonian University. Types of treatment include chemotherapy, immunotherapy, surgery and radiotherapy. Patients are also treated at ten hospitals in Cracow.



Registry structure and methods

The registry is a part of the Epidemiology Unit of the Centre of Oncology Maria Skłodowska-Curie Memorial Institute, and receives financial support from the Ministry of Health and Social Welfare. The staff consists of an epidemiologist, four registrars, a statistician and one computer programmer.

Notification of cancer cases or suspected malignant neoplasms has been compulsory in Poland since 1952. All hospitals and outpatient clinics must report all cancer cases on special cards, which are submitted to the registry. In the registry, each new notification is compared and checked with the main database of cases already registered.

The registry also conducts active registration by checking hospital records, pathology records and death certificates. Patient follow-up is carried out by the registry every year through the checking of medical records and death certificates. If no data about cancer patients are available, information is collected via the Address Office in Cracow.

Quality control of the data is done using the IARC-CHECK programme and other programs developed in the registry.

Use of the data

The registry publishes an annual report of cancer incidence and mortality by sex, age, primary site and place of residence. In addition, the registry prepares survival analyses of cancer patients.

The Cracow Cancer Registry is participating in the EUROCARE international, multicentre studies on survival and care of patients. The registry also participates in studies on childhood cancer incidence and survival.

The registry data serve as a basis for planning of cancer control programmes and epidemiological research as well as for education of clinicians and postgraduate students in the field of cancer prevention.

Source of population

1998–2001: population estimates. 2002: Census.

Multiple primary rules used

IACR rules (2004) on historical data.

Notes on the data

The Editors recommend that some care be taken in the interpretation of these data; see Chapter 5 (Categorisation). This registry has the lowest histological verification rate in the monograph.

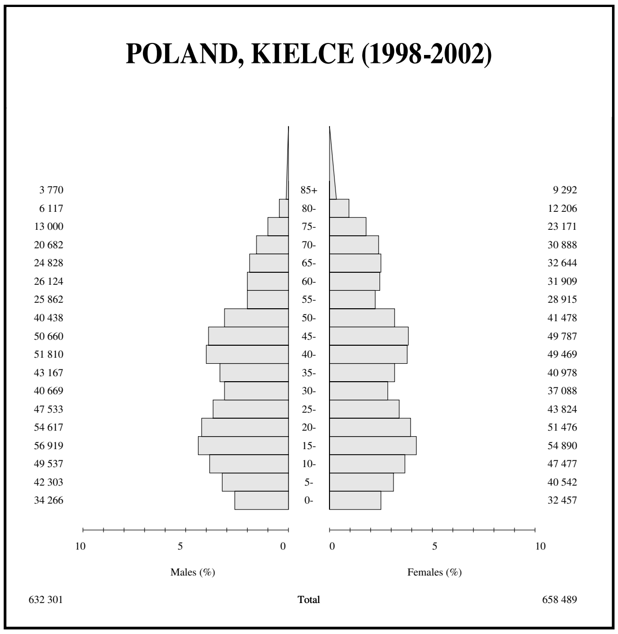
Poland, Kielce

Registration area

The registry covers the Holycross Province (area 11 691 km^2), one of 16 provinces in Poland. It is located in the south-eastern part of the country between latitudes 50° and 51° N and longitudes 19° and 21° E.

The Holycross Mountains (with mountains about 600m above sea level) are situated in the northern part of the province. In the south there is a fertile agricultural region. The Vistula (Wisła) river forms the province's southeastern border. The annual average temperature is 6.9° C (max. 32.9° C and min.-33.9° C). Annual rainfall amounts to about 565mm.

The population as of the official statistical office estimate (30 June 2000) was 1 325 000 (about 3% of the Polish population), with 49% males and 51% females. Of these, 47% lived in towns and 53% in the country. The population of Holycross province is predominantly white race belonging to the Slavonic group; 95% are Roman Catholic.



Cancer care facilities

The Holycross Cancer Centre is located in Kielce, the capital of the Holycross province, and provides various services in the field of treatment (oncological surgery, chemotherapy, radiotherapy, brachytherapy, hematology, endocrynology, palliative care) and diagnostics (e.g. radiology, nuclear medicine, microbiology).

Registry structure and methods

The Holycross Cancer Registry is a department of the Holycross Cancer Centre; its full name is Department of Epidemiology and Cancer Control, Regional Cancer Registry. It is managed by a physician oncologist, one full-time biologist and four full-time registrars. The Registry closely cooperates with the IT department in data processing and statistical analysis.

All medical centres are obliged to report all cases of cancer on a special notification form that includes basic demographic and diagnostic information. These notification forms are the main sources of information on cancer incidence.

Although cancer reporting is obligatory, it is often neglected, and therefore all the received records are completed and checked by the registry staff against data obtained from local civil departments and hospitals.

The National Cancer Registry of Poland evaluates our incidence data every year. In 2002 the completeness was 100%.

Interpreting the results

In 1999, administration reform took place and the area of our registry was enlarged, and the population increased. In 1999 we changed from ICD-9 to ICD-10, and in 2002 we changed morphology from MOTNAC to ICD-O-3.

There are some organised and opportunistic screening programs for breast cancer, prostate cancer, colon cancer and cervix uteri cancer, and PSA testing is common.

Use of the data

The registry maintains two basic files: a computerised file containing the patients' serial number, sex, name and surname, date of birth, date of the first cancer diagnosis, ICD code and year of death (if applicable), and a file containing cards of first and follow-up registration arranged according to information mentioned above.

The registry prepares an annual report on cancer incidence and mortality for local government as well as sending the incidence data to the National Cancer Registry of Poland. The Registry cooperates with the European Network, IARC and IACR, and is a member of ENCR.

We report regularly on extent of diseases. The Registry is not involved in epidemiology research. Policymakers use our cancer registry data but (in our opinion) not in a sufficient way.

Every two years incidence data are sent to the National Cancer Registry of Poland, which publishes bulletins of cancer incidence in Poland.

Source of population

Central Statistical Office in Poland.

Multiple primary rules used

IACR rules (2004) on CI5 IX period.

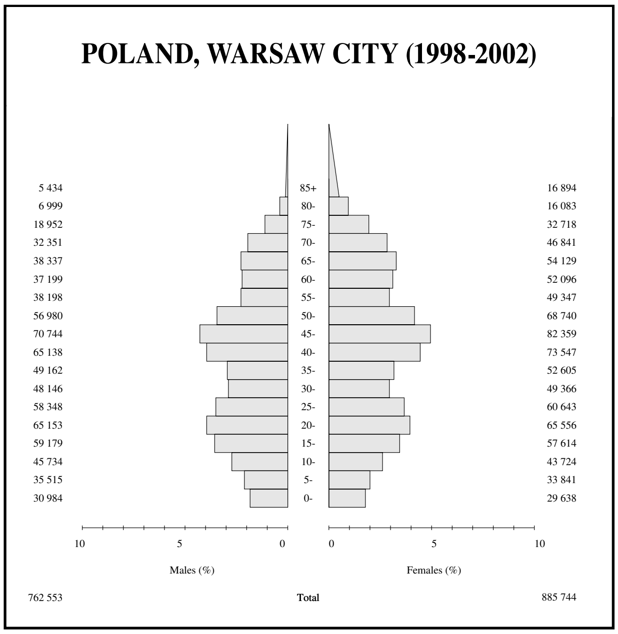
Poland, Warsaw

Registration area

In the years 1963–1988 the Warsaw Cancer Registry collected data on the population living in Warsaw city and selected rural populations in the provinces of Warsaw, Ciechanow, Plock and Siedlce. In 1989–1998 the Registry collected data on the population in Warsaw city and six voivodships (the Province of Warsaw, Ciechanow, Ostroleka, Plock, Radom, and Siedlce). After 1999 this area became one voivodship (Mazovian). The Mazovian Province covers an area of 38 000 km^2, 12.5% of the total Polish territory. The area is inhabited by 5 112 000 people (13.5% of the total Polish population).

Warsaw, the capital of Poland and the largest centre of the Mazovian Province, is a major industrial centre in Poland lying on the river Vistula, in the Mazovian Lowland in eastern central Poland, at 52° 16’ N and 20° 59’ E. The registration area amounts to 495 km^2, populated by 1 673 000 persons. The average altitude is 100m above sea level.

The population structure by sex and age groups was analysed on the basis of data released by the Central Statistical Office of Poland, valid by June 30 every year. The population-at-risk is the average of the population at 30 June of each the years 1998 through 2002, estimated on the basis of the 1988 Census population. The population is ethnically little differentiated, and mostly Roman Catholic.



POLAND, WARSAW CITY (1998-2002)

Cancer care facilities

Poland is divided into 16 regions with regional oncological centres localised in each of them. Nationwide supervision is performed by the Maria Sklodowska-Curie Memorial Cancer Center and Institute of Oncology in Warsaw and two branches in Cracow and Gliwice. Provincial Oncological Clinics provide oncological diagnostic and therapeutic health services, including radiotherapy, in each of Poland’s 16 provinces. The oncologists are usually concentrated where the oncological centres are located.

In Warsaw, specialised cancer care is provided by the Maria Sklodowska-Curie Memorial Cancer Center and Institute of Oncology, clinics of the Medical Academy, the Institute of Mother and Child and Center of Child Health. Patients are also treated at other hospital wards in Warsaw, district outpatient clinics and specialist private and public centres, as well as cooperatives and foundations. Warsaw has over 400 oncologists and 1000 oncological beds.

Registry structure and methods

The Warsaw Cancer Registry was one of the first Registries in Poland, established in 1963 in collaboration with the USA National Cancer Institute to conduct comparative studies on gastric cancer incidence in Poland and among Polish-Americans. These studies were subsequently extended to other cancers, and registration now embraces all sites. The registry is located at the Maria Sklodowska-Curie Memorial Cancer Center and Institute of Oncology in Warsaw, the institution responsible for organising nationwide epidemiological studies, scientific research, and therapeutic services related to cancer. It is supported by the Ministry of Health and Social Welfare. The total database now contains over 70 000 records from the old database (Warsaw and Selected Rural Areas: 1963–88), and over 260 000 from the new database (1989–2005). The Registry now contains over 50 000 records from the old database (1963–1986) and over 100 000 from the new (1987–2005).

The recording and reporting on a special reporting card of every case or suspected case of malignant neoplasm by all health service institutions and individual physicians has been compulsory in Poland since 1952. Information about cancer-related deaths in Warsaw in 1998–2002 was taken from death certificates issued by the Central Statistical Office of Poland. Since 1989 the database has been maintained in a computerised file arranged by patients’ names, date of birth and cancer site, and a card file containing the first registration and follow-up cards arranged by sex and registration number.

The epidemiological data on cancer incidence in 1998–2002 in Warsaw were collected from the Cancer Reporting Cards (MzN-1) routinely submitted to the Warsaw Cancer Registry. The data collected are recorded on reporting cards and include personal identification data (name and surname, sex, date of birth, address, occupation); medical institution; date of first diagnosis/first hospital admission; primary site, pathology, clinical stage, method of diagnosis, methods of treatment, and (if applicable) date of death.

The reporting cards are sent from hospitals and outpatient clinics from Warsaw city, the region and other areas of Poland; for all from oncological outpatient clinics, medical records departments, and other cancer registries. New notifications are immediately checked for consistency of the identifying data. When more than one neoplasm is observed, with other histopathology, in the same person, a new card is prepared for each different site. All entries are checked for duplicates. Site is coded to ICD-9 (to 1998), to ICD-10 (from 1999) and histology to MOTNAC. Active and passive follow-up continue until the patient’s death. If current data about the patient’s vital status are unavailable, information is requested from the Address Register.

Interpreting the results

The percentage of underregistration was estimated in Poland in 1998–2002 at about 12%; however, in Warsaw underregistration is lower. In Warsaw there are organised screening programs for the cancers of the cervix uteri, breast in women and for the cancers of colon and prostate.

Use of the data

The data are analysed to describe the patterns and trends of incidence and mortality by sex, age groups and cancer site in Warsaw. Clinical stage is also analysed for selected cancers. Survival studies are conducted, as well as analysis of treatment regimes for some sites. The data are published in annual reports, monographs, and other publications and papers. They are also used in many research projects and international collaborative projects. Policymakers use registry data for health services planning and evaluation.

Source of population

The estimation of the population at risk is based on the 1988 census, making allowance for births and deaths.

Multiple primary rules used

IACR rules (2004) on CI5 IX period.

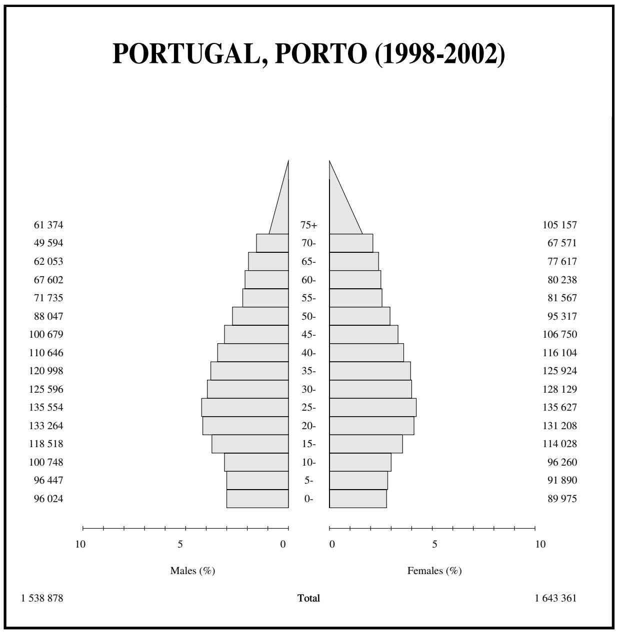
Portugal, Porto

Registration area

The Registo Oncológico Regional do Norte (RORENO) registers all new cancer cases of the North Region of Portugal. According with the last census, in 2001, the population was 3 236 089 inhabitants distributed in five districts (Porto, Braga, Viana do Castelo, Vila Real and Bragança). The population reveals a relatively young age structure, and is fairly unevenly distributed, its density in Porto being 53 times greater than in the easternmost parts of the region.

The Portuguese population is remarkably homogenous and has been so for all of its history. Legal immigrants represent around 1.5% of the north population, and the largest communities are from Brazil, Cape Verde and Angola and lately from Eastern European countries. Around 96% of the population is Roman Catholic.

Some specific areas such as Ave and Minho-Lima are highly industrialised, mainly in textiles, clothing, footwear and furniture. The mountains on Northwest and the eastern region are predominantly rural areas with little socio-economic dynamism. The world's first demarcated wine region is located in the Douro Valley where Porto wine grapes grow.


PORTUGAL, PORTO (1998-2002)

Cancer care facilities

Porto is home to the main cancer treatment centre of the north region, the Instituto Português de Oncologia do Porto, which provides radiotherapy, surgery and chemotherapy for all patients. In Porto there are also two general hospitals capable of providing cancer treatment. Some kinds of cancer may be treated in the other districts. The health system is based on a network of primary health centres and is supplemented by private clinics and laboratories.

Screening programmes are mostly opportunistic and include cancers of the breast, cervix, prostate and colorectum. In 2001 population-based screening for breast cancer began in Bragança, involving 22 541 women.

Registry structure and methods

The registry is located in Porto at the Instituto Português de Oncologia, which is responsible for the co-ordination and organisation of the program and for the quality of its data. In 2000 a medical epidemiologist, two full-time registrars and a part-time statistician staffed the registry. Two medical pathologists were also included as consultants. The staff is responsible for treating the incoming information from the health institutions and also for quality evaluation.

The main method of data collection is passive notification of the cases. The majority of the information on classification of cancer arrives already coded (ICD-O-1). In 2000, 81.4% of the registrations (32 sources of data) were coming from public health institutions and 18.6% from eight private pathology laboratories and hospitals.

Since mid-June 2005 every hospital has had the ability to send the data via a common website: www.roreno.ipoporto.min-saude.pt.

Although the registry was built on a legal framework, access to a unique personal identification number is denied. Our main problems concern the promotion of the follow-up of all the cancer cases, access to digital death certificates and the completeness of some items as address and age.

Interpreting the results

There has been an improvement on completeness of data and for most cancer sites; incidence rates must be close to reality. Some undiagnosed cancers concern mainly those with clinical and radiological diagnosis only.

Uses of the data

Every year since 1988 an annual report of cancer incidence in the North Region has been published. Childhood cancer data were used for a few master's theses and for epidemiological studies. The registry receives weekly data requests for epidemiological studies on risk factors and survival. A study on quality (accuracy) of the data was published in 1995. Registry data have been used to support some projects of the Regional Health Administration, namely in planning of screening services.

Source of population

1998–2000: Official numbers for population in the north region, for years between census. For the year 2000, only age groups of 10 years were published and freely available. These estimates allow for births and deaths and to migration movements. 2001: official census.

Multiple primary rules used

IACR rules (2004) on CI5 IX period.

Notes on the data

The Editors recommend that some care be taken in the interpretation of these data; see Chapter 5 (Categorisation).

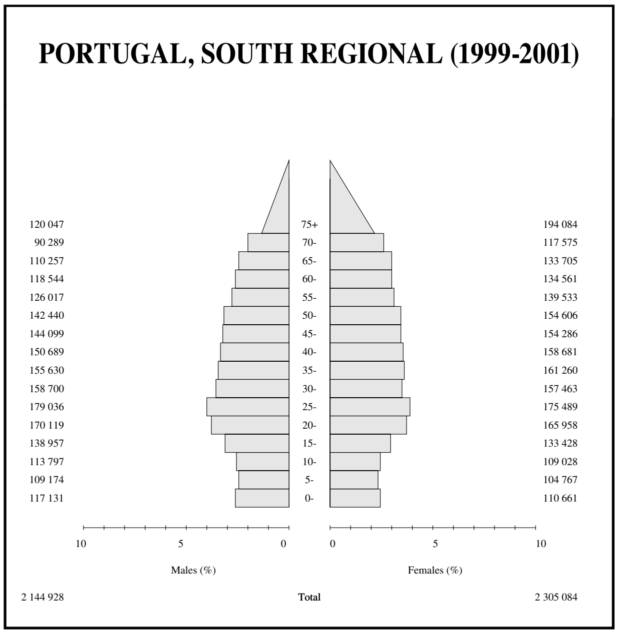
Portugal, South Regional

Registration area

The South Regional Cancer Registry (ROR-Sul) is the population-based cancer registry responsible for cancer registration in the south of Portugal. Its area of activity includes the Lisbon area, Alentejo and Algarve regions, and Madeira Autonomous Region, covering approximately half of the country (39 700 km^2) both in terms of area and population.

According to the end-of-year 2001 estimates, ROR-Sul has 4 490 491 inhabitants, 17.5% of them aged 65 or more. Of these, 45% live in the Lisbon region (capital of the country and suburbs). Birth rate in 2001 was 10.9%, and life expectancy was 73.5 for men and 80.3 for women.

The occupational distribution by economic sector in the 2001 census was distributed as follows: 5% agricultural, 35.1% industry and construction, and 59.9% services.



PORTUGAL, SOUTH REGIONAL (1999-2001)

Cancer care facilities

General health care in the region is provided by 40 public general hospitals, one university hospital, a network of 147 primary health care centres and Lisbon's Cancer Institute. There is one general practitioner per 2000 inhabitants. Almost all cancer patients are diagnosed and treated by medical specialists working at the hospitals.

Registry structure and methods

South Regional Cancer Registry began operation in 1989 as part of a programme for nationwide cancer registration, and is financed by public health funds.

Since 2000 there has been a registry network; data are collected by laptop computer from all hospitals and health centres, and by means of standardised paper forms for private hospitals and pathology labs and for annual follow up. The laptop is under the control of one clinician at each site. The Registry network server is located in Lisbon's Cancer Institute.

The permanent staff of the Registry network includes two physician specialising in epidemiology, one of them as head of the registry, three statisticians and ten tumour registrars. In addition, two consultants—one pathologist and one oncologist—are available.

The Registry is based on compulsory reporting of all new cases since 1988. The first tumour identifier is the pathology report from all hospital and private pathology labs. Necessary information is abstracted from the medical records in each hospital or health centre by trained tumour registrars or local physicians and entered into the central server via the network. In addition, hospital discharge files of cancer patients, and hospital pharmacy and radiotherapy service records are compared with registry database, and all the cases not in the registry are reviewed.

Site and morphology codes have been coded according to ICD-O-3 since 2000. The rules used for coding multiple tumours are those proposed by IARC/IACR. For the staging of tumours, the TNM classification is used.

Completeness of records, data consistency and duplicate records are continuously and extensively checked using the IARC-Check program, other specific computer program developed in the registry, and by reviewing a sample of cases.

Arrangements have been made with the other two Regional Cancer Registries in order to exchange information on those resident cases diagnosed and treated in hospitals outside the registration area.

Patient follow up is carried out every year by checking death certificates.

Use of the data

The main purpose of the registry is to estimate cancer incidence in the region, and annually the registry prepares a report on incidence. In addition some case–control studies have been carried out.

The registry also participates in several national and international research projects, including EUROCARE.

The registry is the recognised regional source of information on cancer incidence. There are often requests for information from physicians, politicians, journalists and interested organisations.

Source of population

The estimates of population–at–risk are based on the 1991 and 2001 Censuses, making allowance of births and deaths. It was not possible to estimate migration into and out of the registration area.

Multiple primary rules used

IACR rules (2000) on CI5 IX period.

Russia, St. Petersburg

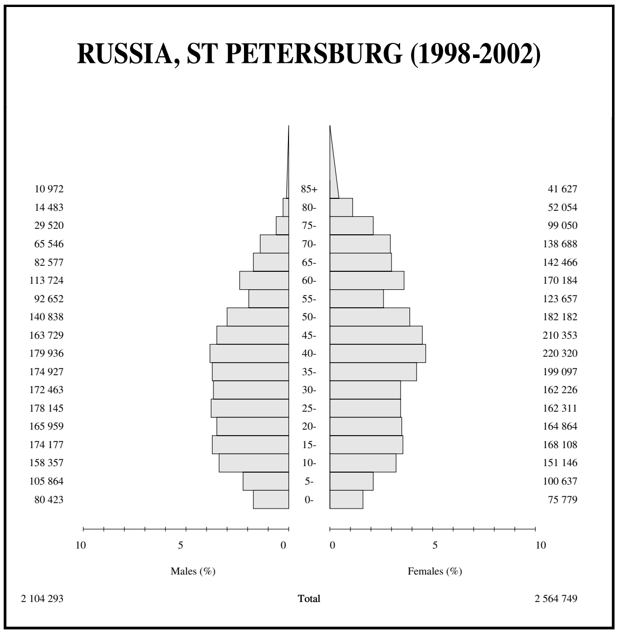
Registration area

St. Petersburg is the second largest city in Russia and one its biggest industrial, scientific and cultural centres. It was founded in May 1703, and in 1914 its name was changed to Petrograd and in 1924 to Leningrad. It was the capital of the state from 1712 to 1728 and from 1732 to 1918. St. Petersburg is situated at the point where the Neva River flows into the Gulf of Finland and includes 42 islands of the Neva delta. The climate is of a maritime type with mild winters, rather cool summers, and very changeable weather. The average temperature in January is -7 -9° C, in July +17.7° C. The annual precipitation is 585mm and the total area is 570 km^2.

The main occupations are heavy industry, especially heavy engineering (energy engineering industry, machine-tool construction, shipbuilding). In 2000 the total population was 4 660 792.

The mortality rate for all causes in St. Petersburg in 2000 was 16.3 per 1000 inhabitants, and the average life expectancy in 2000 was 66.0 years.

The national structure of the population in St. Petersburg according to the census of 2002 was 3949.6 thousand Russians (84.7%), 87.1 thousand Ukrainians (1.9%), 54.5 thousand Belorussians (1.2%), 36.6 thousand Jews (0.8%) and 35.6 thousand Tatars (0.8%).


RUSSIA, ST PETERSBURG (1998-2002)

Cancer care facilities

There are three medical institutes and two advanced training institutes for doctors, as well as a large number of clinics and hospitals. Some of the patients come from other parts of the country. Treatment of cancer patients is carried out mostly in the City oncological dispensary at the Professor N. N. Petrov Research Institute of Oncology, or in a number of oncology departments in large general hospitals. The total number of oncological beds is 1252, including 428 radiological and 75 paediatric. Ordinary hospitals and clinics treat 40% of oncological patients.

Since 1953 in Russia there has been an established state system of oncological services (cancer control). Each administrative territory has its own centre (an oncological dispensary) with 200 to 1000 beds depending on population. This oncological centre provides all three components of curative treatment (surgery, radiotherapy and chemo-hormonotherapy). In general this therapy is free of charge using federal funds as well as funds of obligatory medical insurance.

Registry structure and methods

The General process of registration is the same as that used across the whole territory of the ex-USSR. A doctor who detects a cancer patient must send a notification card to the oncological dispensary or the cancer registry for the region of residence of the patient. On the basis of this card and other supporting documents a control card is compiled and entered into the computer. The data of the oncological dispensary are checked regularly against those of the statistics department, which is responsible for registering cancer deaths.

Interpreting the results

There are screening programs, but since 1991 they have been performed less actively. PSA testing is used but not widely because of financial difficulties.

Use of the data

Information about all cancer patients and about deaths is included in special tables, which are sent to the Russian Ministry of Health annually.

N. Toichkin made the first evaluation of cancer rates in St. Petersburg in 1912. His research was based on the cancer mortality rate of 93–99 per 100 000 inhabitants in St. Petersburg from 1901 to 1910, which he obtained from the municipal statistics department.

In 1926 N. N. Petrov initiated an institute of oncology in St. Petersburg, which was later named after him. Obligatory registration was attempted in St. Petersburg in the 1930s and was permanently adopted after the Second World War. Epidemiological research is carried out in the Petrov Institute of Oncology, including a study of cancer incidence in different areas of the ex-USSR.

Annually we publish 1–2 editions on morbidity and survival. Additionally we systematically take part in different conferences and have TV and radio presentations. Data of the Cancer Registry are systematically presented to the local government, and they are taken into account in developing the organisation of oncological services to the population. Our suggestions to develop establishment of further cancer registries are accepted in a draft of the Order of the Ministry of Health concerning improvement of oncological services in Russia.

Source of population

Official governmental estimates based on the 2002 census. (Committee on Statistics of St. Petersburg).

Multiple primary rules used

IACR rules (2000) on historical data.

Serbia

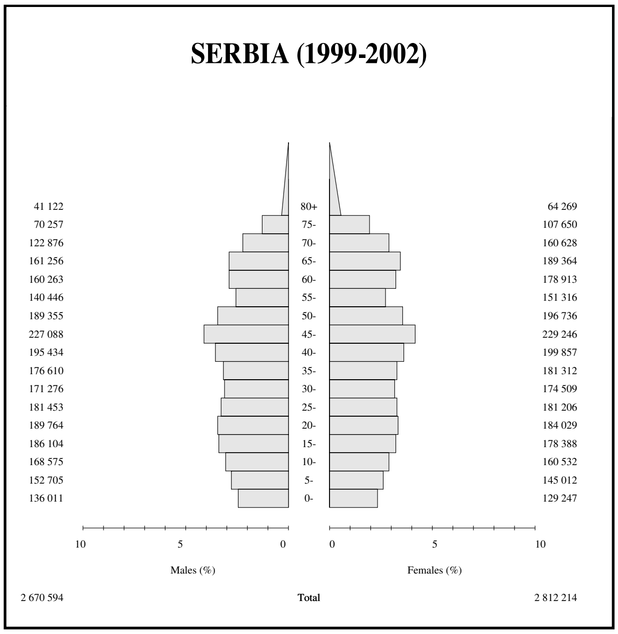
Registration area

The Population Register for Cancer was formed in Serbia in 1970, originating from the Plan of Statistical Research of Interest for the Republic of Serbia. In the 1990s the data quality and the functioning of the registry greatly improved.

The Central Serbia Cancer Registry covers an area of 55 968 km^2, and had a population of 5 484 920 (June 2000 estimate). About half live in urban areas (48.7% male, 51.3% female); 90% are Serbs and 60% are Orthodox Christians. Central Serbia includes 18 districts, in the central part, within the Republic of Serbia, divided into 115 municipalities.

Cancer care facilities

Notification of neoplasms is mandatory by law for every physician who diagnoses or treats a malignant tumour. Information sources concerning new cancer cases/ deceased cases are data from the oncology institutes, oncology dispensaries, oncology clinics, hospitals and outpatient health institutions, pathohistology/cytology, haematology and other laboratories, death reports, health insurance funds and targeted researches. The notification is sent to a regional Cancer Registry located in the Institute of Public Health of Serbia.


SERBIA (1999-2002)

Registry structure and methods

In 1986, with the aim of applying a unified Registry methodology in all territorial units of the Former Yugoslavia, the Guidelines On Ways And Procedures Of Reporting Persons With Malign Neoplasms, the Regulation Book For The Register Form And The Method Of Updating, The Report Forms And Reporting And Cancelation Procedures For Certain Diseases were adopted.

Imprecise guidelines, insufficient education of medical personnel, and a lack of informatics support resulted in the under-registration of newly found cases of cancer, as well as relatively poor data quality on the report forms themselves. Starting from legal obligations and role of the Registry, the reorganisation of the Register began in 1996, in accordance with the recommendations of the International Agency for Research on Cancer (IARC), and European Network of Cancer Registries (ENCR). The reorganisation encompassed: decentralisation (registers are formed on a regional level, while the main database for Central Serbia is located in the Institute of Public Health of Serbia), active data collection, new sources of information, education of medical personnel, informatics support and a feedback system. In 1998, due to this successful reorganisation, the Central Serbia Cancer Registry was admitted into the IACR.

The Central Serbia Cancer Registry includes the following data: personal characteristics of new cases/ deceased, possible appearance of multiple primary tumours, date of determination of current illness, diagnostic methods, tumour characteristics (primary and secondary anatomy localisation, histology type, stage), outcome of the disease, as well as data on the health institution reporting the tumour.

Interpreting the results

Since 1994 the diagnosis, cause of death and morphology have been coded using ICD-10, and according to the ICD-10 and ICD-O-2 (1998) and ICD-O-3 (2001). The Register does not include *in situ* tumours (codes D00-D09), but includes clinical stage *in situ*.

The Register is supported by the CanReg3 (1998) and CanReg4 (2001) programme packages.

With the aim of providing quality in collection, entry, keeping, processing and analysis of data in the Registry, the methodology of international associations was applied (IARC I ENCR) for cancer registers.

Use of the data

Following the aforementioned activities and the several years necessary for achieving stability of the data, conditions were created for issuing the first Report in December 2001.

Unpublished data of the Republic Statistics Institute were used for the analysis of death due to malignant tumours in Central Serbia.

Apart from crude rates, the Report includes standardised incidence and mortality rates on World population. These rates were standardised by the method of direct standardisation, with the World, European or truncated population as the standard population. Registry data calculated and analysed at the Center of Prevention and Control of Noncommunicable Diseases have been used for the purposes of descriptive epidemiology.

The percentage of new malign tumour cases registered on a death report only basis, as well as the percentage of histologically and cytologically-verified malignant tumours of the total number of reported cancer cases, were the foundation for the evaluation of Registry data quality.

Source of population

The populations for 1999, 2000 and 2001 are estimates provided by The Statistical Office of Republic of Serbia. The estimated populations were an extrapolation from the 2002 census assuming linear growth in every age and sex group.

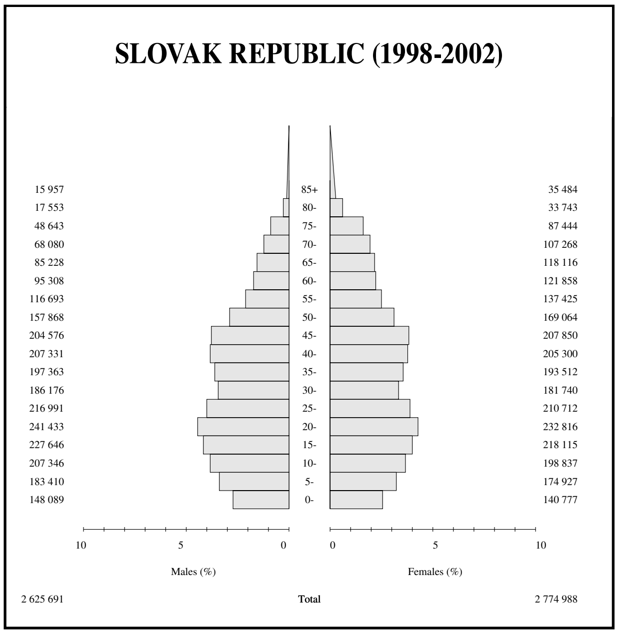
Multiple primary rules used

IACR rules (1990 and 2000).

Slovak Republic

Registration area

The National Cancer Registry of the Slovak Republic covers the whole population of the Slovak Republic, with 5 400 679 inhabitants (2 625 691 males and 2 774 988 females) in 2000. The Slovak Republic is divided into 8 regional units and 79 districts and covers an area of 49 035 km^2, with a perimeter of 1672 km and a population density of 110.1/km^2. In 2000 nearly 13% of the inhabitants lived in the two bigger cities, Bratislava and Košice. Twelve percent lived in another nine towns with 50 000–100 000 inhabitants, 30.4% in communities and smaller towns of 5000–49 999 inhabitants, and the remainder in villages with fewer than 5000 inhabitants. In 2000 the majority of the working population was employed in industry and agriculture (37.8%), the remainder being employed in building and service industries, research and trade. In 2000, employees in the Slovak Republic could be divided by education into four categories: basic (9.1%), trained (29.2%), secondary (48.8%) and university (12.9%). The majority of the population is of Slovak nationality, the second most numerous group being Hungarian. Unemployment was 18.3% in 2000, but 9.6% at the end of 2006.



SLOVAK REPUBLIC (1998-2002)

Cancer care facilities

In 2000 there were 95 hospitals in the Slovak Republic. There were 92 public (state) hospitals and hospitals with polyclinics (7 university hospitals, 79 hospitals and 6 psychiatric hospitals) and 3 private hospitals. Cancer care at the highest level is provided by the St Elisabeth Cancer Institute and the National Cancer Institute, both in the capital of Slovakia. There are oncology and radiology departments at the university and most of the county hospitals. The peripheral network of oncology outpatient clinics is oriented to registration and notification of diagnosis, active lifelong follow-up and providing treatment for cancer patients. The creation in 2000 of the Eastern Slovak Cancer Institute has also contributed to improving high-level cancer care and, in general, the quality of diagnostic and treatment services for cancer patients is gradually improving.

Registry structure and methods

The National Cancer Registry of the Slovak Republic is a population-based cancer registry established in 1976. It covers the entire population of the country and collects cancer data from the year 1968 onwards.

Cancer reports and death notification forms are used for data collection. The registry has had its own computer centre since 1990. In 2005 it moved from the National Cancer Institute to the National Centre for Health Information, Bratislava. The staff of the registry now consists of one epidemiologist, one full-time and four part-time physicians (oncologists and pathologists), seven registrars and one computer specialist. Notification of cancer is compulsory, and all physicians have three months to complete the notification forms.

The registry notification form is completed in the district oncology outpatient clinics. Further information from the clinics is provided about change of name, address, diagnosis and about the death of any cancer patient. In the registry each newly notified patient is compared and checked with the main file of patients already registered to ensure proper registration of new primaries and elimination of duplicates. All death certificates (all causes of death) are regularly reviewed to ensure the inclusion of previously unregistered cases and consequently to include DCO cases.

The National Cancer Registry database is annually reconciled with the database of hospitalised patients (established by the Ministry of Health). If any cancer report is missing, it is searched for and requested of the provider.

The completion of dates of death is now also assessed using data from the Office for the Evidence of Population of the Slovak Republic. Since 1990, the registry has received considerable information about cancer patients from other documents accompanying the notification form (discharge summary, hospital record, operation report, results of histology or cytology and autopsy report).

Interpreting the results

There was no national screening programme in 1998–2002, although screening for colorectal cancer was introduced in 2002 and PSA testing is widely available. An increase of *in situ* cervical cancer and a decrease in breast cancer mortality despite increasing incidence would suggest the existence of some screening programmes or at least an improvement in diagnosis and health education. The national screening programme for cervical cancer became available in 2007.

Use of the data

Annual reports have been published regularly since 1983. The annual report contains detailed data on cancer incidence in Slovakia, including sub-regions, and is distributed to all the health institutions of the country (Ministry of Health, central institutes, hospitals, centres of clinical oncology, public health institutes). The data are used for policy preparation for cancer care and prevention, as well as for planning facilities for the diagnosis and treatment of cancer patients. Recently these data have been increasingly used by the National Centre of Health Promotion and by the Slovakian League Against Cancer, mainly for health education of the population in the field of cancer prevention.

The data are also used for many other international collaborative projects.

Source of population

1998–2000: estimates. 2001: Census. 2002: estimates (Statistical Office of the Slovak Republic).

Multiple primary rules used

IACR rules (2004) on CI5 IX period.

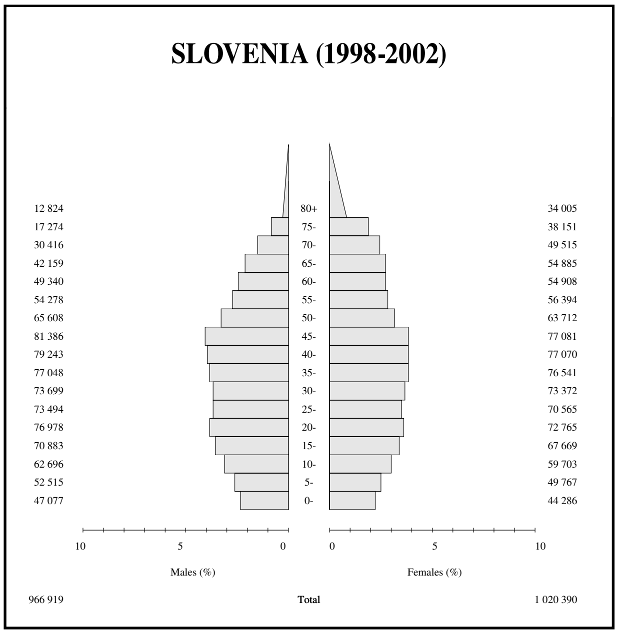
Slovenia

Registration area

The Cancer Registry of Slovenia covers the entire population of the Republic. The population at the most recent census (2002) was 1 964 036. About 50.8% of the population lives in urban areas (>3000 inhabitants); 83.1% are Slovenians, 2.0% Serbs, 1.8% Croats, the remainder other nationalities, mainly from neighbouring countries and countries of former Yugoslavia. The prevailing religion is Roman Catholic, and 84.7% of population is aged 15 years or over.

Cancer care facilities

Health care centres and private practitioners provide primary and outpatient secondary health care; most of them are included in the public health care network. There are 12 general hospitals and Clinical Center in Ljubljana as a tertiary healthcare facility. The Institute of Oncology, founded in Ljubljana in 1938, is the only Slovenian national comprehensive cancer centre. Besides patient care, it is involved in research and education in the framework of the University of Ljubljana Medical Faculty. Common cancers are treated in general hospitals, though the Institute of Oncology is the referral centre for rare cancers. Except for skin cancer, radiotherapy is administered only there. About half of cancer patients are admitted to the Institute at some time during their illness.



Registry structure and methods

The registry was founded in 1950 and is located at the Institute of Oncology Ljubljana. Notification of cancer has been compulsory since the beginning and is prescribed by law. In 2003, the Registry was merged with Epidemiology Unit in a single service, Epidemiology and Cancer Registries, which also comprises, the hospital-based Cancer Registry of the Institute of Oncology, Epidemiology Unit for epidemiological studies and Cervical Cancer Screening Registry, which coordinates, monitors and evaluates the nationwide organised cervical cancer screening program, introduced in 2002. The Registry is staffed by two full-time medical doctors, specialising in epidemiology and public health, a junior researcher in statistics, 4 registrars, a computer operator and part-time system analyst. Other staff are involved in screening and other work.

The main sources of data are notifications gathered from all hospitals and diagnostic centres in Slovenia, and exceptionally from primary health care centres in cases in which the patient was not referred for further diagnostic investigations. Death certificates and autopsy protocols stating cancer diagnosis supplement this information. When needed, requests are sent to notifiers to ensure accurate information as well as to the hospitals or doctors who signed the death certificates in case the patient had not yet been registered. Trained registrars, supervised by a physician, perform coding of the information. Case identification is based on a personal identification number that also enables accurate follow-up of patients for death by regular linkage of our data to the Central Population Register. Data protection regulations are strictly respected.

Interpreting the results

The small and stable proportion of cases registered after the publication of annual reports (about 4%) shows that the majority of cases are reported to the Registry by the time of publication. The registration of patients treated in the outpatient department only (e.g. non-melanoma skin cancer, multiple myeloma, chronic lymphatic leukaemia, as well as prostate cancer) is incomplete.

There are no official data on PSA testing, but it is becoming very popular among urologists. It is not paid to general practitioners by health insurance.

Use of the data

Annual reports on cancer incidence have been published since 1951, since 1965 in Slovenian and English. The data collected serve as the basis for assessing the national cancer burden, for programming and evaluation of primary prevention, diagnosis, treatment and rehabilitation, for programming and evaluating primary prevention, diagnosis, treatment and rehabilitation, planning facilities and funding needed for cancer control (personnel, equipment and hospital capacities) as well as for clinical and epidemiological research in Slovenia and in international multicentric studies. The results of our studies are published in national and foreign medical literature and as publications for lay readers.

Our data have been published in all eight volumes of the Cancer Incidence in Five Continents. The data on cancer incidence and mortality for the years 1983–99 were also included in the international databases EUROCIM, GLOBOCAN, ACCIS. The survival of Slovenian cancer patients is included into and analysed by the international studies EUROCARE II and EUROCARE III.

Source of population

Official number of the population as at 30 June provided by the Statistical Office of the Republic of Slovenia based on the Central Population Register of the Republic of Slovenia.

Multiple primary rules used

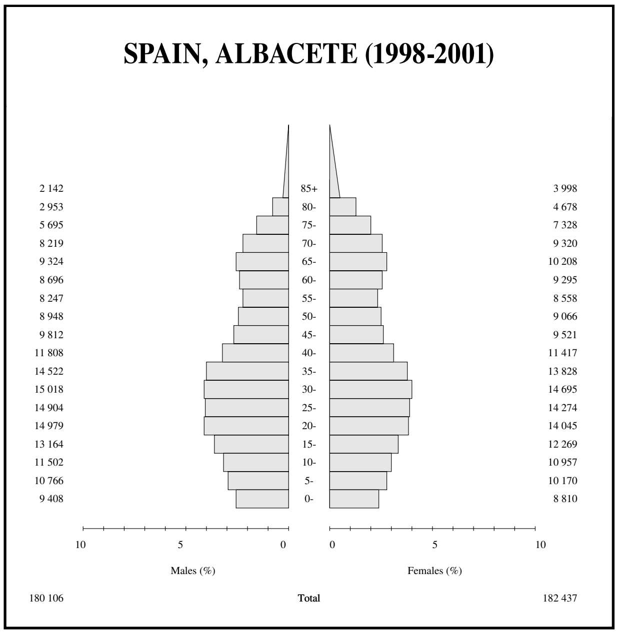
IACR rules (2004) on historical data.

Spain, Albacete

Registration area

Albacete is situated in the Central Meseta in the southeast of Spain. The province consists of 87 municipalities, 67.5% of which have fewer than 2000 inhabitants and only 5.9% have more than 10 000. The climate is Mediterranean temperate with some continental features. The average total annual rainfall is approximately 275mm.

The size of population covered by the registry at mid-year 2000 was 363 263 inhabitants. The population density (24 inhabitants per km^2) is very low compared to that of the country as a whole. Of this population, 15.5 % live in rural areas of fewer than 2000 inhabitants, 24.5% in semi-rural areas of 2000-10 000 inhabitants, and 60.0% in urban areas.


SPAIN, ALBACETE (1998-2001)

The ethnic/racial composition that our Registry covers is practically all white. Only in recent years have immigrants accounted for 3–5% of the population, and these are generally young people with low risk of cancer.

Cancer care facilities

Six hospital centres are located in the province, three of which are private surgical hospitals and three public general hospitals. There is one private pathology laboratory. There are 34 public primary care centres. Almost all of the population is covered by the public health system (SESCAM).

Data for the registry are obtained from the General Hospital of Albacete (pathology and haematology laboratories, oncological and medical records departments); the Local Hospital of Hellin (pathology and haematology laboratories and medical records); the hospitals N^{a} S^{a} de los Llanos; Santa Cristina, Virgen del Rosario and Clinica de Recoletas; the Dr Iñiguez de Onzoño pathology laboratory, the Provincial Office of SESCAM, the regional mortality register and the National Institute of Statistics.

In general our area has a good availability of diagnostic and treatment services, but the radiotherapy department did not begin operation until the year 2002.

Registry structure and methods

The Cancer Registry of Albacete was created in February 1990 by the Consejería de Salud de la Comunidad Autonoma de Castilla-La Mancha, and it belongs to the Regional Service of epidemiology with the principal objective of analysing cancer incidence in the province. It is financed by the Comunidad Autonoma. Our Registry currently employs 2 doctors and a nurse.

Data collection is active, carried out by the personnel of the registry from lists provided by the sources, and by consulting the files and clinical records concerned. The registry records cases voluntarily notified by physicians in the primary care services.

No active follow-up of cases is carried out. The registry has access to death certificates mentioning cancer for local residents who die in the Autonomous Community. Death certificates are traced back to find further information if the case is not already registered, and if no further information is found the case is registered as death certificate only. There is no personal contact with patients or their families.

All data are automatically processed using a system, which includes checking for duplicate registrations by name, social security number or clinical record. Cases are coded by ICD-O topography and morphology. Multiple tumours are coded following the IARC/IACR recommendations. The CHECK program is used to detect errors and discrepancies in the data.

Interpreting the results

It is not possible to estimate how many cancer cases remain undiagnosed, but it probably does occur for elderly subjects in rural areas. SESCAM has a full range of diagnostic facilities, so it is unlikely that cases referred will be missed. A screening service for breast cancer is operated by the Asociación Española contra el Cáncer since 1991. Use of PSA tests is opportunistic and of an unknown extent, but in general it is not uncommon.

Use of the data

The registry prepares an annual report of cancer incidence by site, sex and age. The registry also participates in analytical epidemiological investigations. Policymakers use our cancer registry data for planning or evaluation of health services, especially in breast cancer screening programme and the regional cancer programme.

Source of population

Census: Instituto Nacional de Estadistica (http://www.ine.es).

Multiple primary rules used

IACR rules (1990).

Spain, Asturias

Registration area

The Asturias cancer registry covers the whole Principality of Asturias, a Spanish Autonomous Community of 10 565 km^2 located on the northern coast of the Iberian Peninsula. This well-defined region lies between latitudes 42° and 43° N and longitudes 4° and 7° W.

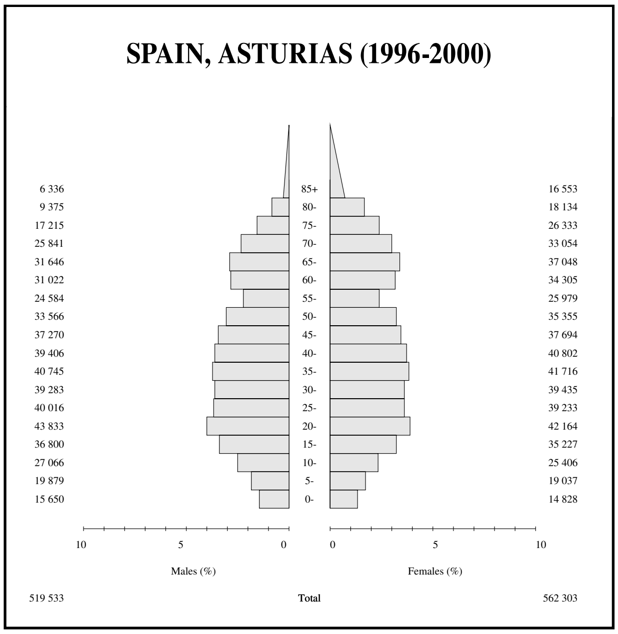
In 2000 the total population was 1 076 567 inhabitants. Of these, 21.4% were aged 65 or more, and 60.4% lived in the central urban area of Asturias but only 43.4% in cities of more than 100 000 inhabitants. The population density that year was 101.53 inhabitants per km^2.

In 2000 the unemployment rate was 16.4% in Asturias, and the distribution of occupation by sector was 10.2% in agriculture and fishing, 16.9% in industry, 11.8% in the building sector and 61.1% in services.

The prevailing religion in Asturias is Roman Catholic.

Cancer care facilities

General health care in Asturias is provided mostly by public services through a well-developed network that comprises 8 district hospitals, 220 urban and local primary health care centres, and Central Hospital in the capital (Oviedo), home to a comprehensive oncology centre that offers cancer surgery, radiotherapy and chemotherapy services. Patients suspected to have cancer are diagnosed and given treatment in the 8 health districts and referred to Central Hospital when required. These facilities are supplemented by one private hospital that offers some cancer treatments. Very few cancer cases require additional treatment outside Asturias.



Registry structure and methods

The registry was initiated in 1978 and become population-based in 1982. It is located in Oviedo and since 1981 has been funded by a Public Health Directorate from Asturias Health and Health Services Council, a government body in charge of planning and providing health care and public health services to the whole Asturian population. The registry staff comprises one part-time epidemiologist and two full time registrars.

The registry uses active casefinding from different sources including public and private hospitals, pathology and haematology laboratories and death certificates to identify cancer cases diagnosed among the residents of Asturias. There is also a hospital-based registry in Central Hospital, which provides computer files to the registry. Cancer is not a notifiable disease in Asturias.

Interpreting the results

From 1998 to 2000 an organised breast cancer screening programme was implemented in Asturias covering women aged 50–64, reaching a 60.5% participation in the first round.

Trends in prostate cancer incidence should be evaluated with caution because the impact of opportunistic PSA screening.

Use of the data

The registry publishes regular reports on cancer incidence. Data from the registry have been used for etiological research in the EPIC cohort, evaluation of breast cancer programmes, and to plan radiotherapy facilities and other cancer services.

Source of population

Census data (INE 2006).

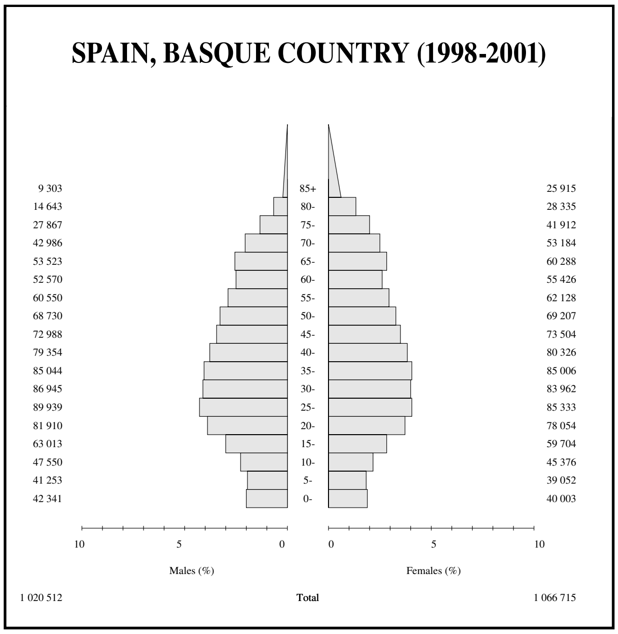
Multiple primary rules used

IACR rules (2004) on historical data.

Spain, Basque Country

Registration area

The area covered by the Basque Country Cancer Registry (BCCR) is the Autonomous Community of the Basque Country, an area of 7261 km^2 situated in northern Spain between latitude 40°27’ and 42°28’N and longitudes 1°44’ and 3°26’W. It consists of three provinces: Alava, Bizkaia and Gipuzkoa. At the 2001 census, the total population was 2 082 587, of whom 17% were over 65 years old. The population density is 286.8 persons/km^2. About 28% of the population live in rural municipalities. The employment of the active population by sector is: services sector 62%, industry 27.5%, building activity 8.7% and agriculture 1.8%. The prevalence of smoking in men and women is decreasing: 31% and 21% respectively. The proportion of immigrants was low but increasing. Most of the population is Roman Catholic.



Cancer care facilities

General health care in the region is provided by the Osakidetza, the public Basque Health Service, to 95% of the population. There are 40 hospitals (public and private, one of them devoted to cancer treatment) excluding the psychiatric ones, and approximately 4 beds per 1000 inhabitants. Most cancer patients attending the network of primary healthcare centres are referred to medical specialists at the general hospitals with oncology facilities. Over the last 10 years the number of radiology facilities for cancer diagnosis and treatment as well as the number of oncology specialists has increased in both the private and the public system.

Registry structure and methods

The Basque Country Cancer Registry was created in 1986 by the Department of Health. The main aim was to determine cancer incidence and its characteristics in the Basque Country, to provide information for the planning of cancer services and preventive activities, and to facilitate epidemiological research.

A major reorganisation of the Cancer Registry has taken place since 1995. In each province a team was defined and five hospital cancer registries were established. The coordination of the BCCR remained in the Health Department (Vitoria-Gasteiz), where a computer technician and one epidemiologist were assigned part-time to the registry. Previously registered cases were converted from ICD-O-1 to ICD-O-2 with IARCtools, and a new data management application was developed. The head of the provincial team, an epidemiologist partially assigned to the registry, and several administrative registrars have the hospital registries as the main sources of information. Notification is voluntary. An active system of data collection from other sources has been established, and cases are abstracted from clinical records and entered in the computer. Data from incident cases are complemented by death certificates mentioning cancer (pre-1996) and all death certificates since then. A case is registered as Death Certificate Only when no further information has been obtained after looking for information in the sources. Checking for duplicates is routine, and the IARC-Check program is used periodically. Arrangements have been made with cancer registries outside the registration area to notify the BCCR of any resident cancer cases they diagnose or treat.

Interpreting the results

Rates from 1986 to 1994 were converted from ICD-O-1 to ICD-O-2. Since November 1995 there has been an organised breast cancer screening programme in the Basque Country covering women aged 50–64 years.

There is no population-based cervical screening programme, but there is opportunistic screening mainly in women at higher risk. The large increase in prostate cancer in recent years can be related to the use of PSA by general practitioners and specialists since 1998.

Use of the data

A report with descriptive results of the registry is published in an annual report by the Basque Health Department. Information provided by the registry is used for planning and evaluation of health services. Survival has been studied in the framework of the EUROCARE study.

Data have been used for the evaluation of the breast screening programme and in several collaborative studies such as EUROCARE, Europreval, ACCIS and EPIC among others. In-house studies include several cancer sites and their relation to health services, and evaluation of coding to implement a semi-automated programme.

Source of population

Estimate of the population at risk is based on the 1996 and 2001 censuses without taking into account immigration into or out of the area.

Multiple primary rules used

IACR rules (2004) on historical data.

Spain, Canary Islands

Registration area

The archipelago of the Canary Islands is one of the autonomous regions of Spain. It is located 100km east from the African coast and 1500km from mainland Spain, between latitude 27° and 30° N.

The Registry covers the population of the two major islands (Gran Canaria and Tenerife), which are the administrative capitals of the two provinces. Those two islands had a population at mid-year 2000 of 1 474 802 inhabitants (population covered by the registry).

The population is almost 100% Catholic although there are some people from India who have lived in the islands for generations. In recent years, especially in 2001 and 2002, the islands have undergone a strong immigration phenomenon, mostly from South America.

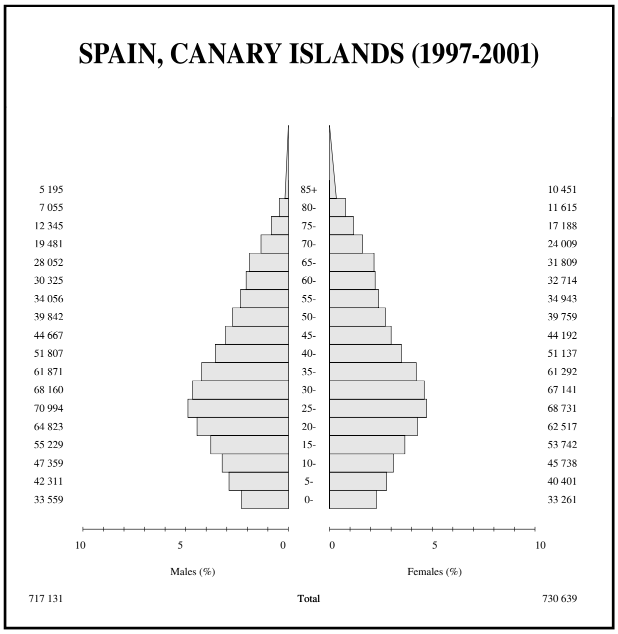
The economic activities are agriculture (7%), industry (3.4%) and services, mainly tourism (77.9%).

Cancer care facilities

There is a network of primary health care centres and two reference hospitals in each island with services of oncology, radiotherapy, haematology and cancer surgery and chemotherapy.

Registry structure and methods

The registry belongs to the Public Health headquarters and is part of the Epidemiology Service. Each island has a team of 2 medical doctors, 2 nurses and 1 clerk.



The Registry actively collects data from public and private sources. Registrars search for cases at pathology, oncology, radiotherapy, and haematology services, in inpatient records and hospital cancer registries, as well as in private pathology laboratories and among death certificates with cancer as primary cause of death.

If necessary, patient medical records are verified by the originating hospitals, either to confirm the incidence date, method or tumour site. Since 2006 we have had internet-based access to the records of the 4 major hospitals, which has been an excellent tool.

Some patients go to hospitals in mainland Spain for treatment, but most diagnoses are made in the islands, and in any case many of these are collected via death certificates, so we believe the registry completeness level is acceptable.

Interpreting the results

There is an organised screening programme for breast cancer in women aged 50–64 years from, and opportunistic screening for cervix and prostate cancer. PSA testing is common in the population.

Use of the data

The registry publicises an annual report of incidence with the cases of one given year, available online at: http://www.gobiernodecanarias.org/sanidad/scs/3/3_5/cancer/ppal.jsp.

The data are used continuously by health managers in health planning for the hospitals and government. The Registry has also conducted some other studies in cancer mortality, and collaborates with several investigations of colorectal, breast, cervix and thyroid cancer and melanoma.

Source of population

1998 Census. Geometrical interpolation between 1996–1999. 1999–2001 Census. Geometrical interpolation between the population on the first day of January of the year, and the population on the first day of January of the next year.

Multiple primary rules used

IACR rules (2004) on historical data.

Notes on the data

C67 includes only invasive tumours.

Spain, Cuenca

Registration area

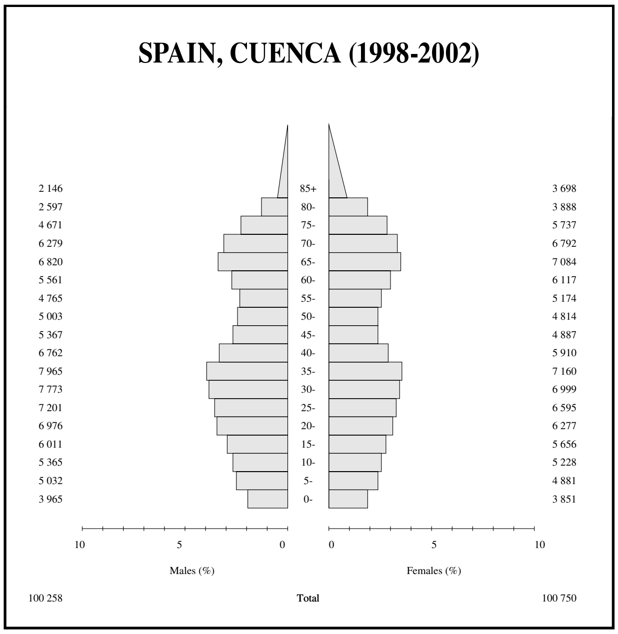
The population-based Cancer Registry of Cuenca was created in 1993, within the Epidemiology Service of the Health Department of the Autonomous Community of Castilla-La Mancha.

The area covered by the Registry is the Cuenca province, located between 40º33’ and 39º35’ N latitude, corresponding to the Spanish Central Plateau.

The population (according to the 2000 census) was 201 060 inhabitants (100 127 males and 100 933 females), including 1289 immigrants; 44% live in rural areas (<2000 inhabitants). Some 25% are older than 65 years, and 14% are under the age of 15. The province covers 17 140 km^2 (238 municipalities), at a population density of 11.7 inhabitants/km^2. The economic activity rate for the population aged 16–65 is about 50%. Economic activity is developed in the services sector (45.1%), in agriculture (25.2%) and in industry and construction (29.7%).

Cancer care facilities

In the registry area there are a public hospital (with 90% of the beds) and a private hospital. In the public hospital, there is an oncology service where chemotherapy is provided, and a surgery service that serves cancer patients. Patients are sent to referral centres for radiotherapy. There are 37 public Primary Health Care Centres covering the province.



Registry structure and methods

The personnel devoted to the Cancer Registry of Cuenca are two physicians, three nurses and a clerk (all part-time).

Data collection is carried out actively by the personnel of the Registry through the review of clinical histories in the hospital or in the Primary Health Care Centres. The registry receives the automated discharge files and the computerised pathology reports from the public hospital. Furthermore, we receive individualised information from the cases treated by general practitioners, and from the hospital physicians who attend patients with cancer, as well as information from death certificates. There is an organised screening programme for breast cancer that also informs us of newly diagnosed cases.

The principal objectives of the Population Cancer Registry of Cuenca are:

1. To know the real incidence of the Cancer in our province, as well as its distribution by age, sex, morphology and topographic site of the different tumours.
2. To compare our incidence with that in other registries in Spain and other countries.
3. To know the temporal evolution of cancer incidence in our province.
4. To know survival rates in cancer patients and their temporal evolution.
5. To contribute to improving and encouraging epidemiological investigation, preventive measures and sanitary care in oncology patients.

Material and methods

All malignant tumours diagnosed from 1 January 1993 in persons residing in Cuenca at the moment of diagnosis are eligible for the RCCU. Furthermore, following WHO recommendations, we register all bladder tumours, independent of their behaviour. Basal and squamous cell skin cancers are not registered.

The data are automatically processed using a system that includes checking to avoid duplication, such as surnames, Social Security number and Clinical History code. We use the CHECK program to detect errors and inconsistencies between the different variables.

Cases are codified according to the ICD-O-2, following the recommendations of the IARC to classify multiple primary tumours as well as to register the different variables (incidence date, diagnosis basis). Access to patient data is restricted to Registry personnel.

Use of the data

The registry publishes a report of cancer incidence from 1993 to 2002, highlighting trends, evaluating survival and making geographical comparisons. Our registry is also taking part in the Regional Plan Oncology in Castilla–La Mancha. The registry also participates in a national research project about rare tumours.

The information obtained was used to produce three incidence posters at the National and Regional Epidemiology Annual Conference.

The data will also be used to measure the effect of the breast cancer screening programme.

Source of population

Updated information from the municipal registers of inhabitants for each year published by the Instituto Nacional de Estadistica (INE http://www.ine.es), except for the population aged less than 1 year in 1998, which was calculated based on annual growth.

Multiple primary rules used

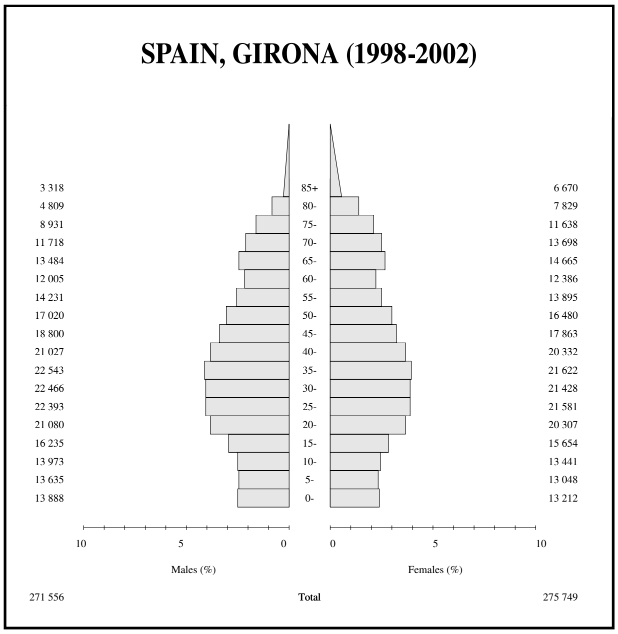
IACR rules (2000).

Spain, Girona

Registration area

The Girona Cancer Registry covers the population of Girona Health Region, located in the north of Catalonia in the northeast of Spain. The population at the most recent census (2000) was 538 139. The area covered by the registry is divided into 209 municipalities, with Girona city the largest (approximately 86 672 inhabitants). Within this region, about 57% of the population live in urban areas (>5000 inhabitants).

The population in Girona province is ethnically very homogeneous, with the majority of the population being Caucasian. However in recent years there has been a huge increase in immigration from Africa. According to the 2001 census in the province of Girona, 7.7% of the population are immigrants, originating from other European countries (1.8%), Africa (4.0%), South America (0.85%) and Asia (0.26%).



Cancer care facilities

Health care is provided predominantly by the National Health Service through the district hospitals and a network of primary health care centres. There are nine public hospitals with 1087 beds and three private hospitals with 233 beds (2.45 beds per 1000 inhabitants). Medical specialties concerning cancer treatment include radiotherapy, cancer surgery and chemotherapy and are carried out at different general hospitals but coordinated by the reference cancer centre in the city of Girona (Catalan Institute of Oncology-Hospital Universitari de Girona “Dr. Josep Trueta”) which has radiotherapy facilities at its disposal. Some cancer patients may be diagnosed in hospitals located in Barcelona (100km from Girona), and the cancer registry also covers such sources of information.

Registry structure and methods

The Girona Cancer Registry began its activities in 1995. It is funded by the Department of Health of the Catalan Government and is carried out by the Catalan Institute of Oncology.

The staff is composed of a director, an oncologist as a coordinator, an epidemiologist, a technical registrar and a clerk. Several oncologists, hematologists, pathologists, computer scientists and statisticians are external collaborators.

Notification of cancer is voluntary. Data collection is active, from 21 sources consisting of general hospitals and pathology laboratories. Data are obtained mainly from admission services and medical records, as well as from pathology, oncology and haematology departments. The death registration system is adequate and complete; every year the registry analyses all death certificates. The registry staff visit the sources, where they check medical records and database of individual departments related to both the diagnosis and treatment of cancers. Their main objective is to identify and abstract information on cases of cancer that have been diagnosed by all methods. Arrangements have also been made with the hospitals located outside the Girona registration area in order to obtain information from patients whose cancers have been diagnosed and treated outside the Girona area. Accordingly, these sources are visited once a year to review these procedures. All records are interpreted and after coding, updated and processed. The registry is organised as a multi-user online database.

Morphology has been coded according to ICD-O-3 since 1998 and site has been coded according to ICD-O-3 since 2000. Before 2000, site was coded according to ICD-O-1 and morphology according to ICD-O-2 since 1993. The rules used for coding multiple tumours are those proposed by IARC/IACR. Quality control of data is ensured through the *DEPedit* programme.

Confidentiality is ensured by the application of the rules proposed by the European Network of Cancer Registries (ENCR).

The estimated completeness for the period 1998–2002, taking into account the proportion of DCN cases, was around 95.7%.

Interpreting the results

A screening program for breast cancer was started in the area covered by the registry in 1999, and there are opportunistic screening services for cervical cancer in the area. Use of the PSA test in the medical practices has also increased during this period.

Use of the data

The information obtained is used to produce annual incidence reports. Data on cancer incidence serve as a basis for health planning. Our registry has carried out and participated in epidemiological studies. Studies on both survival and care of patients with some specific tumours are also being carried out.

Source of population

The 1998, 1999, 2000 populations are intercensal estimates based on the 1996 and 2001 censuses, where allowance for births, deaths and migration have been made. The 2001 and 2002 populations are postcensal estimates, where the same methodology used in 1998–2000 has been applied, without making any correction based on a later census.

Multiple primary rules used

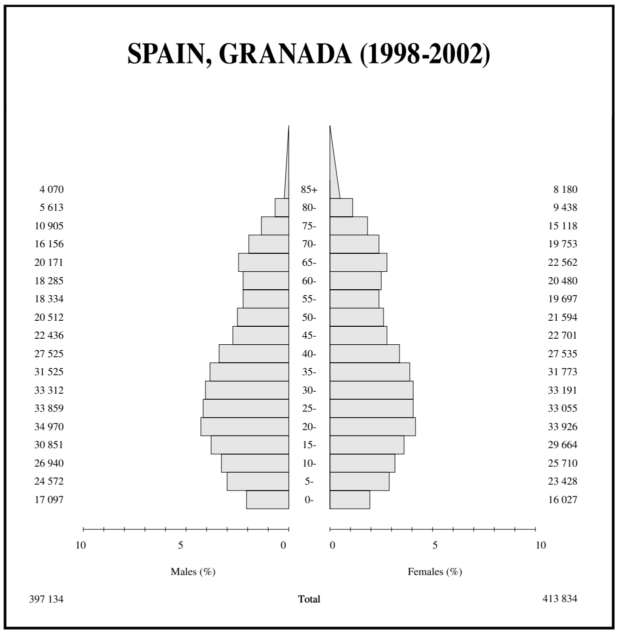
IACR rules (2004) on historical data.

Spain, Granada

Registration area

The population covered is the province of Granada within the Andalusian Region in the south of Spain. It lies between latitudes 38° and 36° N, and has an area of 12 635.3 km^2. The province has 71km of coast along the Mediterranean; a large part of its territory is mountainous, and one of the highest summits of Spain is found there (Mulhacén, 3481 m).

The population in 2000 was 809 006 inhabitants (395 659 men and 413 347 women), 16% of them aged 65 years or more. The province is divided into 168 municipalities: there is only one urban centre (Granada) with approximately 240 000 inhabitants, and 6 other municipalities have more than 20 000 inhabitants, the rest of the population (56%) living in smaller municipalities. The population is ethnically very homogeneous.



Granada has been one of the Spanish provinces with the lowest income per inhabitant, an important factor influencing migratory movements from 1950 to 1970, which have since stabilised. Of the economically active population, 10% are employed in agriculture, 22% in industry and building, and 62% in services. Industrial activity is limited to light industry, particularly food and wood processing. The rate of unemployment is 7% of the active population.

Cancer care facilities

The entire population (100%) has free access to public hospitalisation. The area is served by four public (2137 beds) and three private (356 beds) hospitals. Private hospitals serve a small part of the population. Diagnosis and treatment of cancer are available within the province, so few cancer cases are diagnosed or treated outside.

Registry structure and methods

The Cancer Registry of Granada was established in 1985. It is supported by the Regional Health Department of Andalucía and run by the Andalusian School of Public Health in Granada.

The main registry staff consists of an oncologist as director, one physician, and three clerks for case-finding and data processing. In addition, one epidemiologist, one statistician and one computer expert (part-time) collaborate with the activities of the registry and research projects.

Cancer notification in Granada is voluntary. The basic information sources include all public and private hospitals of the province. The registry receives the automated discharge files for the hospitals and the computerised pathological reports from the public hospitals. Data collection is mixed: incorporation of the automated hospital systems and active complementary search in hospital records by the registry staff. Information based on primary health care is limited. Due to confidentiality requirements, access to death certificates at the National Statistics Institute is not possible, and registry personnel have to collect this information in each of the municipalities. Coverage of this source was about 90% until the year 2000. From this year the access to this source is forbidden.

Data processing is carried out on a personal computer, and quality control of the data is ensured through the IARC-CHECK programme and other specific programmes developed in the registry.

Interpreting the results

Undiagnosed cancer cases are unlikely because diagnosis and treatment (radiotherapy and chemotherapy) of cancer are available in the province of Granada. From the year 2000 it is not possible to use death certificates as a source for case-finding, and this could slightly decrease the degree of completeness, although the percentage of DCO in the previous period was quite low (4%).

An organised population-based breast cancer screening programme has been established gradually in the province of Granada since the year 1997. Opportunistic PSA screening for prostate cancer could be responsible for the increase of prostate cancer incidence rates in the area.

Use of the data

In addition to incidence figures and descriptive studies, some case–control studies on lip, skin and oral cavity cancer have been carried out. The registry is also involved in studies on care and survival of cancer patients within the framework of the EUROCARE study, and in a cohort study on diet and cancer (EPIC Project).

Source of population

Updated using municipal registers of residents as of 1 January. Instituto de Estadística de Andalucía (IEA). Consejería de Economía y Salud.

Multiple primary rules used

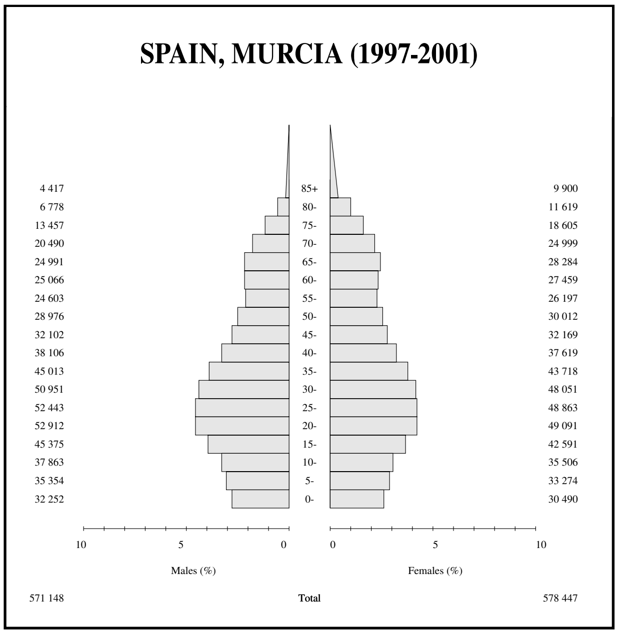
IACR rules (2004) on CI5 IX period.

Spain, Murcia

Registration area

The Murcia Cancer Registry (Registro de Cáncer de Murcia) covers the whole region of Murcia, one of the 17 autonomous communities of Spain. This region is situated in the southeast, a Mediterranean area. The average density is 118.1 inhabitants. The region is divided into 45 municipalities. Approximately 53% of the population lives in three municipalities with more than 50 000 inhabitants, while 7% lives in rural areas (<10 000 inhabitants). The main cities are Murcia, the capital, with 409 818 inhabitants, Cartagena with 203 945 and Lorca 87 153.

The population (2000) was 1 149 328, of whom 17.7% are children. Nearly 11% of the working population is employed in agriculture, although the proportion has been decreasing during the last decades; 62% work in services and 27% in industry and construction. The region has an important food-processing industry. Adequate food consumption frequencies are observed in most of the population for fruit, dairy products, olive oil and protein foods such as poultry, eggs and fish. Consumption of red meat is higher than recommended. Two in three people are overweight. The prevalence of smoking in 2002 was 41% in males and 34% in females, showing an increasing trend for women and a decreasing one for men. During the last decades the city of Cartagena had severe air pollution problems, mostly due to industrial emissions.


SPAIN, MURCIA (1997-2001)

Cancer care facilities

Primary health care and hospital treatment are provided free of charge to every member of the population through a National Health Service. The region is divided into 6 health districts, each with at least one public hospital. There are 25 Hospitals, 12 public and 13 private hospitals for a total of 4317 beds, 73% of which belong to public hospitals, although practically all private beds may be used by the public health service by agreement.

Patients suspected to have cancer in the primary and secondary care facilities in the registry area are referred firstly to local public hospitals, and secondarily to the reference hospital located in Murcia, which has a comprehensive cancer Radiotherapy Unit.

Registry structure and methods

The Murcia Cancer Registry (Registro de Cáncer de Murcia, RCM) was established in 1981 as a project of the *Consejería de Sanidad* of the Region of Murcia, developed by the Department of Epidemiology. The database is registered at the Spanish Data Protection Authority as stipulated by law.

Information is principally collected by registry personnel. The identification of new cases is done mainly through the pathology, hematology, oncology, radiotherapy, outpatient clinics and clinical departments of public hospitals. Registry staff abstracts medical records to complete cancer data. In private hospitals the main sources of information are pathology laboratories and medical record departments. In order to ascertain cancer patients who are treated out of the region, the RCM receives notifications from the National Registry for Childhood Cancer (RNTI) as well as from the social security reimbursement service, which refunds expenses for being treated in hospitals out of the Region of Murcia.

In 1996, a new semi-automated program was developed. All previously registered cases were converted from ICD-O-1 to ICD-O-2 with IARCtools and, in addition, a considerable number of cases were manually reviewed.

When cancer is mentioned on a death certificate (DC), and the Registry has no information on that case, the main files of the principal hospitals are searched. If the case is not found, the certifying physician is questioned. If the information gathered is sufficient to register the case, that case is registered as a Death Certificate Notification (DCN). If no other information is available apart from that on the DC, the case is accepted as a Death Certificate Only (DCO). Both DCO and DCN, among other indicators, are used for monitoring quality control.

Interpreting the results

Opportunistic screening for cervical cancer is carried out by public and private healthcare, increasing the number of Pap tests from the eighties to the nineties, but there is a low number of total cervical cytology compared with the rest of Spain. The PSA testing is an irregular practise in the region of Murcia operating by the cancer society and clinicians. A population-based screening programme for breast cancer started at the end of 1995 with a current participation rate near 70% of the total female population in the region.

Use of the data

The main purpose of the Registry is to estimate cancer incidence in the region, trends and survival. In addition, the RCM is used for planning and evaluation of cancer control programmes as well as for epidemiological studies. The RCM has participated in two multicentre case–control studies, one on HPV and cervical cancer carried out in Colombia and Spain, and another on non-melanoma skin cancer in four Mediterranean countries (initially Helios I Project and afterwards Helios II Project). Currently it is involved in the European Prospective Investigation on Nutrition and Cancer (EPIC study), coordinated by IARC.

The registry participates in EUROCARE, following up cases diagnosed between 1990 and 1998 to provide data and contribute to calculating survival throughout Europe. The Registry is also involved in two multicentre Spanish studies, the first in rare tumours and the second in validating the cancer diagnoses in the minimum dataset from hospitals.

Source of population

Annual estimates: Updated using municipal registers of residents as of 1 May of 1996, 1997, 1998, 1999, 2000, 2001. Madrid, INE.

Multiple primary rules used

IACR rules (1990).

Spain, Navarra

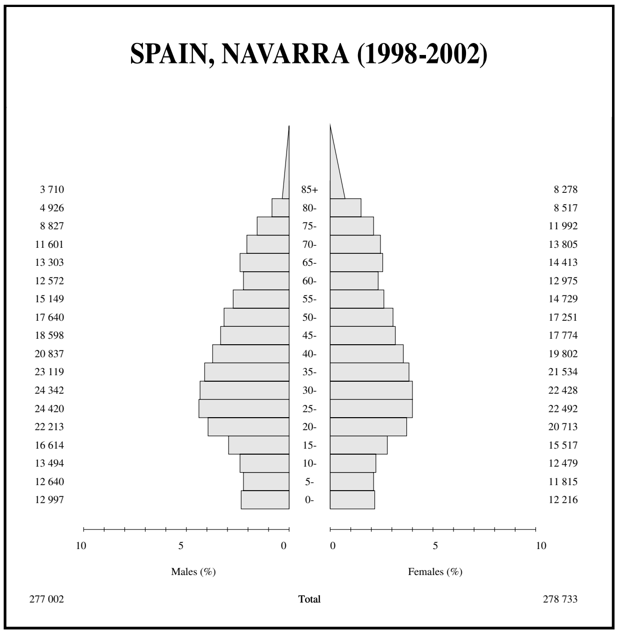
Registration area

The area covered is the Community of Navarra, one of the 17 Autonomous Communities of Spain. Situated in the north of the peninsula, Navarra borders on France to the north (the Pyrenees), the Autonomous Community of Aragón to the east, the Autonomous Community of La Rioja to the south and the Autonomous Community of the Basque Country to the west.

The total area of Navarra is 10 491 km^2. Navarra is scantily populated, with a density of 49.6 inhabitants per km^2, and is the fifth least inhabited Community in Spain.

According to the 2001 census, Navarra had 555 829 inhabitants, of whom 33.5% lived in Pamplona, capital of the province—rising to 50% if the surrounding area is included with the city. Of this population 49.8% are men, 13.7% are aged 0–14, and 18.1% are 65 or over.

In the last decade Navarra has had a small positive migratory balance, as well as a significant re-distribution of the population toward Pamplona and its surrounding area. There are more births than deaths, and the population has grown older over the last years due to the large decrease in mortality. During the last 25 years, the birth rate fell from 17.72 in 1975–76 to 10.04 in 2001. The mortality rate adjusted for the European population in the period 1995–99 was 774.8/100 000 inhabitants for men, and 410.9 for women; in 2000–04 it was 691.6 and 368.1, respectively. During 2000–04, life expectancy for those born in Navarra was 77.9 for men and 85.0 for women.


SPAIN, NAVARRA (1998-2002)

Cancer care facilities

The Navarra Health Service covers 95% of the population. Health care in Navarra is composed of basic health districts, which are grouped into three health areas. All inhabitants have access to the health system through the primary level (Health and Consultation Centres), or through the emergency departments at the primary or secondary (specialised) level.

Cancer control activities in the region are based on promotion of healthy lifestyle, health checks for people occupationally exposed to carcinogenic substances, and hepatitis B vaccination in childhood. There is breast cancer screening in women aged 45–69, cytology screening for cervical cancer among groups considered to be at risk, and *ad hoc* advice to the population. Any patient suspected of having cancer has access to any diagnostic and treatment facilities considered necessary, and is followed by public assistance services and/or by private services.

Registry structure and methods

The population-based Cancer Registry of Navarra was created in 1970, as a result of the collaboration between the Spanish Association Against Cancer and the Public Health Institute of Navarra. The main objective is to study the incidence and principal characteristics of cancers occurring in Navarra, to promote and facilitate epidemiological investigations, and to provide data for planning of health services and preventive activities.

The registry staff includes one part-time epidemiologist, and a full-time nurse and a social assistant who are responsible for casefinding and coding. An administrator records and processes the data. The Advisory Committee of the Navarra Cancer Registry collaborates with the staff. The data are processed in the Registry itself.

Active casefinding involves systematic collection of information on all cancer cases diagnosed in hospital departments in Navarra. Notification of cancer is voluntary. The principal sources of information are the pathology and haematology laboratories, radiotherapy and oncology departments, as well as the medical records departments of all public and private hospitals. Data on incident cases are completed by data on deaths obtained from the Mortality Registry through a systematic search, mainly for completing the cause and date of death.

Follow-up is carried out through examination of medical records and death certificates. There is no personal contact with patients. Data are recorded on individual notification forms and later entered onto computer with a system of individual access for each registry staff member. Duplicate and quality control checks are run periodically. The IARC rules are used for multiple primaries.

Interpreting the results

During this period, no changes occurred in the area covered, although the number of inhabitants increased by 6.7% between 1996 and 2001. The aging of the population is to be taken into consideration: at the time of the 1996 Census there were 14.3% population under 15 years and 17.4% over 65 years. There have been no changes in the availability of diagnostic services and/or treatment.

In 1993, topography and morphology were coded using CIE-0-2 for Oncology. During 1993–2002, the European Network of Cancer Registries recommendations on incidence date and behavioural classification in bladder cancer were applied. Since 1995, all tumours of the Central Nervous System have been collected.

Since 1990, there has been a breast cancer screening programme for women aged 45-64, raised to age 69 for the years 1998–2002. The increase of prostate cancer incidence rates could be due to increased use of the PSA test during this period.

Use of the data
The registry produces local reports on cancer incidence in Navarra for biennial and quinquennial periods. It has collaborated in evaluation of the breast cancer screening programme in Navarra. The registry has participated in two case–control studies on cancer of the cervix and of the larynx, and in a study on brain cancer. It is collaborating in the EPIC study as well as in studies of trends and of childhood cancer. The registry participates in EUROCARE and the EUROPREVAL group. It has been providing data to Cancer Incidence in Five Continents since Volume III, as well as to the ACCIS and EUROCIM databases of IARC.

Source of population
Intercensal estimates. Instituto de Estadística de Navarra. Gobierno de Navarra. http://www.cfnavarra.es/estadistica/agregados/poblacion/estim_censo/estim_censo_9602.xls.

Multiple primary rules used
IACR rules (2004) on CI5 IX period.

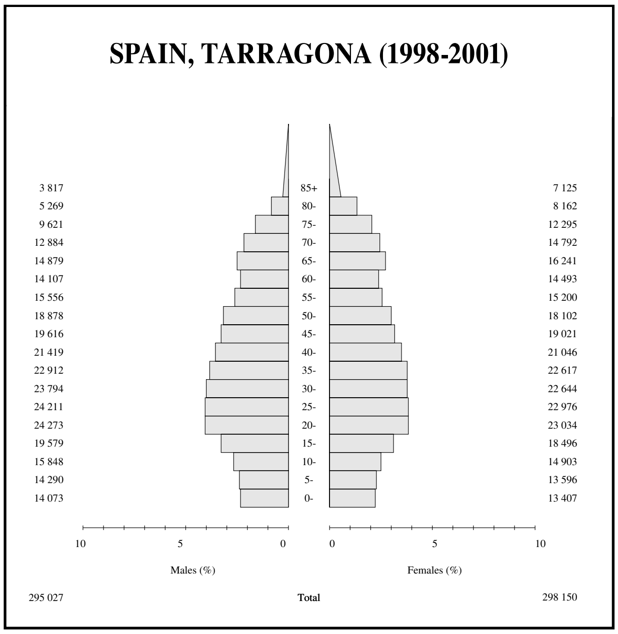
Spain, Tarragona

Registration area

The Tarragona Cancer Registry covers the province of Tarragona, located in the south of Catalonia in the northeast of Spain next to the Mediterranean Sea. In July 2000 the population was 595 652. The two largest towns have 114 000 and 89 000 inhabitants respectively. Five other towns have more than 20 000 inhabitants, 26 other towns have 3000–20 000 inhabitants and 147 villages fewer than 3000.

Approximately a third of the population was born in other parts of Spain and migrated between the 1950s and 1970s. About 20 000 foreigners are officially residents in the province (among them, more than 8000 from Morocco and 7000 from Europe). Since the establishment of the Registry in 1980, there have been no changes in the area covered by it, although the population increased from 513 000 in 1980 to 607 000 in 2001. Most of the people belong to the white Mediterranean race. Roman Catholicism is the major religion.

The prevalence of smoking in people aged 15–64 was 55% in males and 20% in females in 1982, and 43% in males and 25% in females in 1998. Of the working population, 7% belong to the agricultural sector, 21% to the industrial sector, 14% to the building sector and 58% to the service sector. In the province there is a petrochemical complex active since the 1970s. Three nuclear power stations have been running from the 1980s; another has been stripped down after running since 1975.



Cancer care facilities

Practically all the population is covered by the National Health Service. In 2000 the number of physicians was around 2000. In the period 1998–2001 there were seven public hospitals and six private ones in the area, with a total of 1250 beds. One of the public hospitals has a 32-bed oncology department that includes medical oncology, radiotherapy oncology and palliative care units. Some cancer patients are transferred to specific hospitals in Barcelona (100km from Tarragona), which are also sources of information for the Registry.

Registry structure and methods

Since 2001, the Registry has belonged to the Foundation League for the Cancer Research and Prevention, which receives financial support from the Department of Health of the Catalan Government. The Registry also receives funds from the provincial administration.

The staff includes a director, two epidemiologists, a computer scientist, a nurse, a medical officer and one clerk. Several specialists (in oncology, pathology, epidemiology and others) act as external collaborators.

Notification of cancer is voluntary. Data collection is through passive notification in the majority of sources and by active search in the rest. The main sources of information are inpatient records, pathology laboratories, hospital-based cancer registries and haematology laboratories. The Registry receives copies of all death certificates of people who were living in the province. Cases notified from a death certificate are systematically traced, and if no further information is obtained, are registered as death-certificate only cases.

The Registry records malignant tumours whether *in situ* or invasive, and includes tumours of the nervous system of undetermined nature. Bladder papillomas, if histologically verified, are not registered. Although the Registry employs a set of rules for the inclusion of multiple primaries, which are more liberal than those of IARC/IACR, the results presented here strictly follow these rules.

The control of duplicates is based on name, birthdate, sex, places of birth and residence, personal identity number and social security number. Online checks are made when entering the data in the computer to detect errors and inconsistencies. The IARC-Check program is used periodically to detect errors and unlikely situations.

From 1998, the Registry adopted the criteria and the codes of ICD-O-3 for recording morphology.

Interpreting the results

Some assessments indicate that the completeness of the Registry exceeds 96–97%.

Since the beginning of the Registry in 1980, availability of diagnostic and treatment services increased, although it is difficult to estimate the influence of these changes in the cancer incidence trends.

There was no population-based cervical cancer screening programme in the area during the period, but an annual average of approximately 36 000 cytological examinations for cervical cancer were carried out.

A population-based breast cancer screening programme started in 1998 for women aged 50–64, raised to age 66 in the second round. The participation rate in the first round was 58%. About 36% of participants of this programme had a previous mammogram within the two years before the mammogram of the programme.

The use of the PSA test was quite high during this period, but the degree of influence of this diagnostic procedure on the prostate cancer incidence rates in Tarragona is not known.

Use of the data

The Registry produces cancer incidence and survival statistics for the area, and describes their major epidemiological characteristics and their evolution. It also promotes epidemiological research and advises policymakers on current and future needs for cancer care services. It collaborates directly in the evaluation of the Breast Cancer Screening Programme of the province, supports the evaluation of cervical cancer prevention and other cancer control activities and evaluates its effects.

Source of population
1998–2001. The intercensal estimates are based on the 1996 and 2001 censuses, making allowance for births, deaths and migrations into and out of the registration area. Population census of 2001. Institut d'Estadística de Catalunya.

Multiple primary rules used
IACR rules (2004) on historical data.

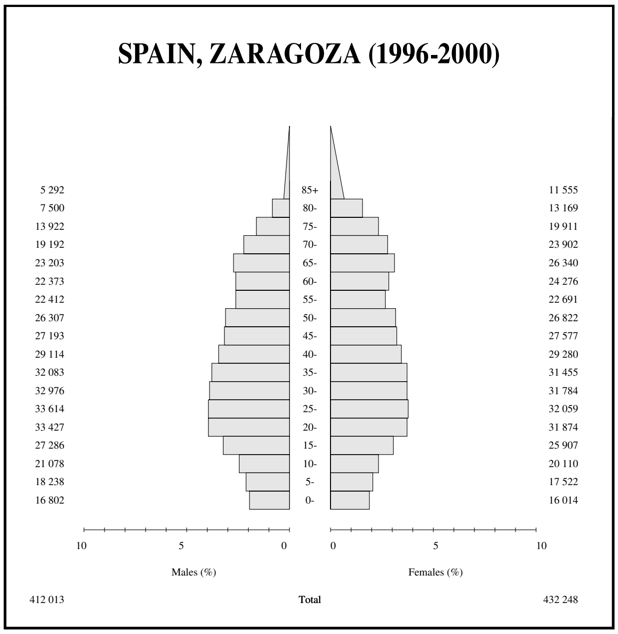
Spain, Zaragoza

Registration area

The Zaragoza Cancer Registry covers the population of one province (Zaragoza) within the region of Aragón, in the northeast of Spain. The population at the most recent census (2000) was 848 006. About 81% of the population lives in urban areas; most are Christians.

Cancer care facilities

General health care in the region is provided predominantly by the Health Services Department of Aragón through a network of primary health centres and public hospitals. This is supplemented by private practitioners and hospitals. The Zaragoza Cancer Registry is located in Zaragoza, the capital of the province, and provides radiotherapy, cancer surgery and chemotherapy services. Patients suspected to have cancer in the primary and secondary care facilities in the registry area are mostly diagnosed and treated in the public hospitals of Zaragoza. We estimate that very few patients are followed outside the registry area.



Registry structure and methods

The registry was funded in 1960 by the state Health Department. The registry is staffed by two part-time medical officers, one part-time administrative worker and one full-time health worker.

The Zaragoza Cancer Registry uses several different sources of data: primarily pathology and haematology laboratories, radiotherapy and chemotherapy services and hospital discharge records. The registry staff visits these sources and records all cases with diagnosis and treatment of cancers diagnosed by all methods, among residents of the registry region. We supplement this information with death certificates when cause of death is identified as cancer.

For some cancers, such as haematological tumours and childhood tumours, complementary information sources (such as the Haematological Registry and the paediatric hospital cancer registry) are used to evaluate the completeness and accuracy of the information recorded.

Interpreting the results

It is not possible to estimate how many cancer cases remain undiagnosed, but it probably occurs only for elderly subjects who have had a pathology diagnosis. PSA testing is common in the population.

In interpreting these results, note that since year 2000 data have been received electronically, as a new method of data collection. Automatic registration began in 2000 as well.

Use of the data

The registry prepares an annual report of cancer incidence, highlighting trends and changes. Some special studies have been carried out. The Registry is participating in several epidemiological studies such as risk of second primary cancers, rare tumours in Spain, childhood cancer trends, incidence and mortality cancer inequalities, the HAEMACARE project and validity of hospital discharge records for estimating cancer incidence. Policymakers mainly use our cancer registry data for planning purposes.

Source of population

Obtained from municipal census.

Multiple primary rules used

IACR rules (1990).

Sweden

Registration area

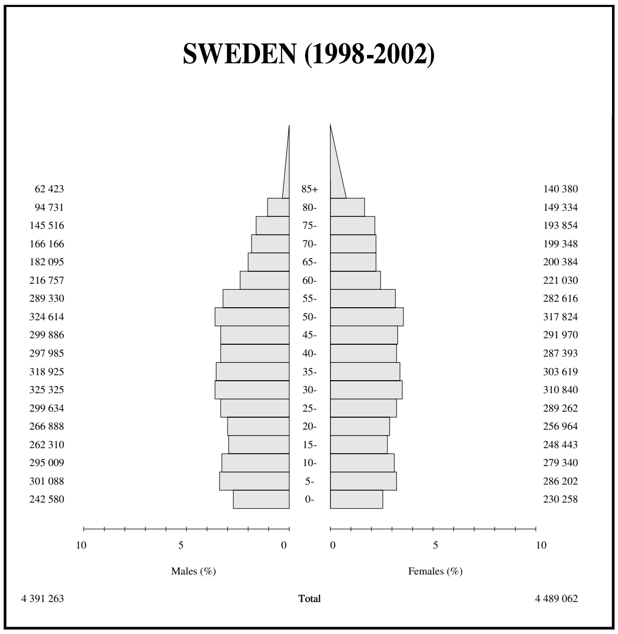
The Swedish Cancer Registry covers the whole population of Sweden. The mean population in 2002 was 8 924 958. About 24% of the population lives in urban areas (>100 000 inhabitants). The main part of the population is Protestant; approximately 15% are not members of the Church in Sweden.

Cancer care facilities

Cancer care facilities in Sweden are incorporated with the general healthcare system. There are oncological centres in each one of the six medical regions of Sweden. Nearly every cancer case will sooner or later be seen at a hospital. Hospital and forensic pathologists make independent compulsory reports on every cancer diagnosis made from surgical biopsies, cytological specimens and autopsies.

Registry structure and methods

The Swedish Cancer Registry, which was established in 1958, is managed by the Centre for Epidemiology (EpC) at the National Board of Health and Welfare. The Government finances the registry. Six regional cancer registries covering the whole country perform the registration of new cancer reports and the major check-up and correction work. These registries are associated with the oncological centres in each medical region of Sweden.



The registration of newly detected tumour cases is based on compulsory reporting by all physicians responsible for in-patient and out-patient departments in all public and private establishments for medical treatment. The data in the Registry are supplemented with information on cause and date of death by computerised linking with the Cause of Death Registry. The Swedish Cancer Registry does not use information on cancers based on death certificates only.

Interpreting the results

The overall reporting to the registry is estimated to be 96% of all diagnosed cases.

There are two main screening programmes in Sweden: breast and cervix cancer. PSA testing for men is also quite common in recent years.

Use of the data

The registry prepares an annual report of cancer incidence, highlighting trends and changes. The publication is, since year 2000, only published on the Internet.

Many researchers in Sweden and in other parts of the world use the registry.

Source of population

Official population statistics from Statistics Sweden.

Multiple primary rules used

IACR rules (2004) on historical data.

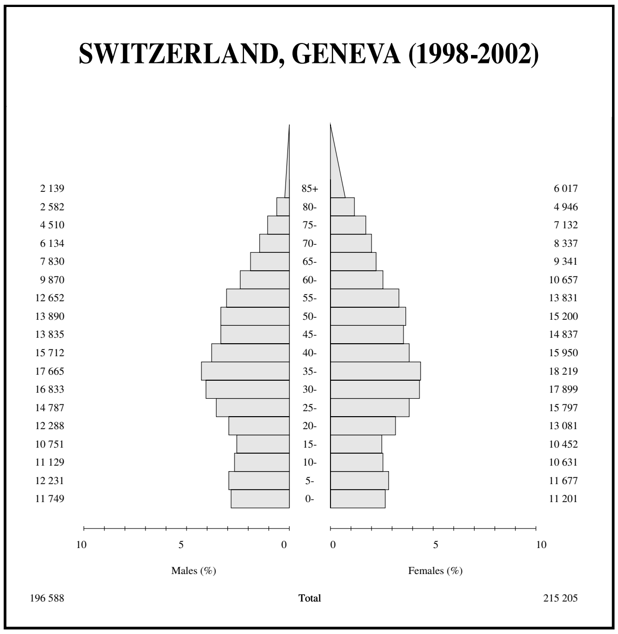
Switzerland, Geneva

Registration Area

The Canton of Geneva is situated at the extreme west of Switzerland. It has a total surface of 282 km^2, of which Lake Geneva occupies 36 km^2. The climate is temperate: mean temperature is 11.5°C, with temperatures varying from -8.8°C to 35.3°C in 2002. The annual rainfall amounts to 1166mm (2002). Air quality is fairly good: the annual average pollutant concentrations observed in the centre of Geneva are 6 μg/m^3 for $S0_2$, 32 μg/m^3 for NO, 42 μg/m3 for NO_2, 34 μg/m^3 for 0_3 and 0.6 mg/m^3 for CO (2002, from ROPAG-SCPA).

On 31 December 2002, the population of the canton was 427 705, of whom 14.5% were aged 65 and more and only 21.9% younger than 20. This structure is due not only to the joint effects of a low fertility rate and an increase in life expectancy, but also reflects fairly heavy immigration (often temporary) at the ages of economic activity. This immigration comes traditionally from Latin countries. Due to a restrictive policy in granting Swiss nationality, the proportion of the resident population considered as foreign remains high, at 38.4%, of which 18% were Portuguese, 14% were Italian, 12% French and 10% Spanish.

The economically active population is concentrated in the administrative and service sectors (82%), with production workers comprising most of the remaining population (16%); agricultural workers are few (<2%), due to the small amount of cultivated land and the high degree of agricultural mechanisation (1995 figures). These figures remain unchanged to date.



Cancer care facilities

The hospital facilities for acute illnesses comprise one general public university hospital with 1267 beds (1997) and some smaller private hospitals and clinics. Cancer patients are also treated at two other university hospitals, namely a geriatric institution (300 beds) and a hospital for chronic affections (300 beds). No hospital, either public or private, has beds reserved specifically for cancer patients. Between 1997 and 2002 there were no major changes.

Registry structure and methods

The Geneva Cancer Registry was founded in 1969 and started recording cases in 1970. In 1991, the Registry was attached directly to the Public Health Service of the Canton of Geneva. Since 1999, it has been attached to the University of Geneva, which provides most of the budget. Additional funds are obtained from the Federal Ministry of Health, through the Swiss Association of Cancer Registries.

The staff is composed of 12 persons, most of whom are part-time, with 3 doctors and 2 statisticians. The registry is located in an apartment opposite the Geneva University Hospital in the centre of the city.

Diagnostic and treatment services are easily accessible: Biopsies are mainly carried out at the central laboratory or in other specialised services of the public hospital. Since two years ago, a large part of the biopsies have been transmitted in electronic form, allowing a linkage with the registry's database each month. There are three private pathology laboratories that provide records to the registry or permit systematic consultation of them. Autopsies are performed at the university hospitals, and the necropsy rate is estimated at 7% of deceased residents (2002). Every case has a personal number for confidentiality.

Data collection for the registry is undertaken by examining the university hospitals records of the various services concerned, as well as by a questionnaire sent out to private practitioners. The response rate of the latter is more than 90%.

We have access to all reports from the only department of radiation oncology in the canton. This department provides us with a control listing each year. The registry also has access to all death certificates in the canton, which in addition to clinical records, permit a continuous follow-up. In addition to this passive follow-up, the registry also undertakes active follow-up of all cases each year. This follow-up is facilitated by direct access to the Cantonal Office of Population. In the case of death, the primary cause is recorded and re-examined, as well as the possible presence of a tumour, clinical or confirmed, at the time of death.

Interpreting the results

As an indicator of reliability of the data, a very low percentage of cases (<1% 1998–2002) are recorded from death certificates only. In addition, the low rate of cases found at autopsy (0.7% 1998–2002) compared with the total number of cases confirmed histologically suggests that most cases are identified during the lifetime of the patient.

During this period 1998–2002, there was not yet a screening program in the canton for any localisation of cancer, but since 1 January 1999 there has been a screening programme for breast cancer. Nonetheless, spontaneous screening is well accepted in the population, with mean annual screening rates of about 40% for Pap tests (women aged ≥15) and about 20% for mammographic screening (1991–1995). PSA testing is generalised in the population of the canton.

Use of the data

Policymakers do not use our cancer data to evaluate health services. For planning, the cancer registry has received an official mandate to evaluate the breast cancer screening program and the campaign against melanoma.

In addition to the processing and publication of routine, incidence and survival data, the registry initiates or participates in analytical epidemiological investigations. Several case–control and cohort studies have been undertaken for etiological or evaluative purposes.

Source of population

Average mid–year annual estimates, based on official numbers of births, deaths, immigrations and emigrations, on December 31st. Office cantonal de statistique.

Multiple primary rules used

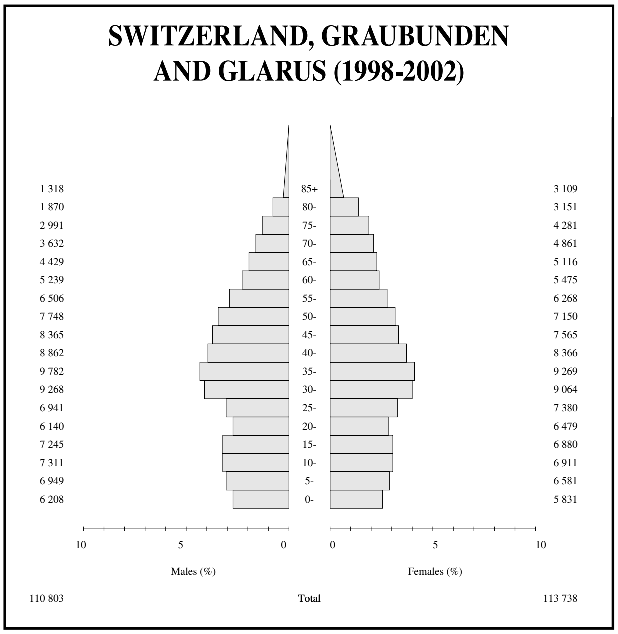
IACR rules (2004) on historical data.

Switzerland, Graubünden and Glarus

Registration area

The cancer registry of Graubünden Glarus covers the population of the two corresponding cantons in the eastern part of Switzerland. The Canton of Glarus has 29 communities and Graubünden 213. The population at the official census 2000 was 36 600 for Glarus and 187 058 for Graubünden. About 15% of the population of Glarus live in the capital of Glarus, while 20% of the population of Graubünden live in the capital Chur. In both cantons about 40% are Catholics and 50% Protestants. Glarus has about 25% foreigners, while in Graubünden there are about 15%. Most are Christians, whereas only a very small minority are Muslims. Only very few people immigrated from African or South American countries.

Among the population of Graubünden, 27 038 were räto-roman, who keep their native language, the *Rumantsch*.


SWITZERLAND, GRAUBUNDEN AND GLARUS (1998-2002)

Cancer care facilities

General healthcare in Glarus is provided by the district hospital in the capital Glarus and a network of about 40 practitioners. In the main hospital, cancer surgery and chemotherapy are available.

In Graubünden cancer care is provided mostly in the main hospital in Chur, which includes all cancer services. Radiotherapy is available only at the centre in Chur; some of the patients are treated in Zurich or St. Gall. A network of some 10 hospitals and about 300 practitioners supplement this care. Altogether 5% of the patients are treated in the cantons of St. Gall, Zurich, Ticino or even at hospitals over the Italian frontier (patients from the Posciavo).

Registry structure and methods

The registry is located within the Department of Pathology at the main hospital at Chur, and is funded partly by the cantons of Graubünden and Glarus, and by the Federal Government of Switzerland. A part-time pathologist (less than 10%) and a part-time registrar (80%) are responsible for the registration of new cases. The method of registration is strongly related to guidelines of the cancer registry network of Switzerland.

About 85% of new cases are directly notified through the pathology network, the reminder being found by case study (scrutinising medical documents) in about 30 departments of 12 hospitals of the two cantons. Notification is based on a voluntary agreement between the medical institutions and the registry. Death certificates are provided by the Federal Office of Statistics by special contract. In fact, there are more and more pre-coded data available, facilitating the registry work. Cancer registries of Zurich, St. Gall and the Ticino complete the datasets with information about patients hospitalised outside the registration area. The network of the registries in Switzerland and the central office help to complete the data files in the registry of Graubünden and Glarus, which in fact needs more personnel. As an active member of the Swiss Association of Cancer Registries, the registry has permission from the Central Data Commission for Data Protection in Medical Research of the Swiss Government to receive non-anonymised data on cancer patients.

Periodically quality control and plausibility procedures are performed partly by the registry itself, partly by the Swiss Association of Cancer Registries.

During the reported period there have not been any changes in the covered area or the population registered. Case definition and coding have been kept stable, except for adaptation to TNM-Classification or the recommendations of the AJCC. Reporting includes incidence and follow-up for periods of 5 and 10 years.

Interpreting the results

Because neither of the two cantons has university service and because a large population live in rural areas, some cancers might go unrecognised. However, the cooperation of the neighbouring cantons ensures that cancers treated outside the registration area are captured.

Still, screening for some cancers (e.g. cervix) is not thoroughly established, and needs further distribution among the rural population at the cantons' periphery. For other cancers, i.e. breast cancer, a screening program is widely accepted. PSA screening for cancer of the prostate is widely accepted and performed. Discussion is ongoing on the possibility of lung cancer associated with exposure to free radicals (i.e. radon) and also to dust-mediated pneumopathies.

Use of the data

The main objective of the registry is to make the data on cancer incidence available to the Swiss Association of Cancer Registries for publication and dissemination. In the future, more active participation in analytical epidemiological investigations is planned. Providing data to policymakers for planning and evaluation of health services has to be established in the future.

Source of population

Annual estimate of permanently resident population at mid–year, based on the 2000 census and taking into account births, deaths and migration. Source: Federal Office of Statistics, Switzerland.

Multiple primary rules used

IACR rules (2000).

Switzerland, Neuchâtel

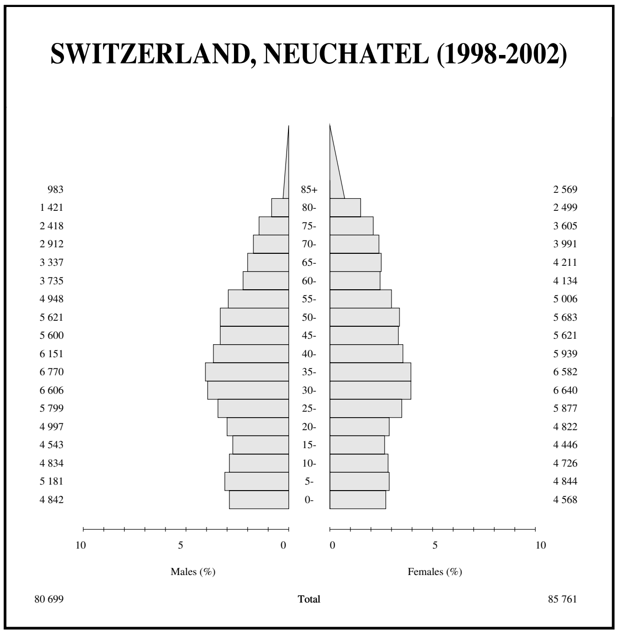
Registration area

The Registry, which covers the whole of the French-speaking canton of Neuchâtel (800 km^2 with about 168 000 inhabitants), is located in the western part of Switzerland, sharing half of its frontier with France. The canton is a mainly rural region with only two cities of approximately 35 000 inhabitants. In the absence of heavy industry, watchmaking and the micro-technical industry are the main activities.

Almost all the population is of Caucasian origin; 38% are Protestant, 31% are Catholic, and foreigners, predominantly of Mediterranean origin, currently account for about 23% of residents. In 2000, the main occupational sectors in the canton of Neuchâtel were: industry 34%, agriculture 4% and services 62%.

Cancer care facilities

In 2000, the region covered by the Registry had around 900 hospital beds available for diagnosis and treatment (i.e. about five beds per 1000 population). In the same year there were about 520 practicing physicians (one per 320 population). Radiotherapy and oncology services are integrated in a unique coordinated multi-site public organisation covering the whole area.



Registry structure and methods

The bulk of information is provided by the local Institute of Pathology (INAP) through biopsy, cytology and autopsy reports. Notification is based on voluntary agreement between the recording medical institutions of the canton and the Registry. Other sources of information are the departments of oncology and haematology, which also centralise diagnostic and therapeutic procedures for malignant haematological disorders.

The Registry is financially supported by the local League against Cancer (60% of the budget) and by the cantonal public health department for the remainder. Marginal support is also provided by the Swiss government through the Swiss Association of Cancer Registries.

Moreover, information on residents diagnosed or treated outside hospital, elsewhere in Switzerland, or in other countries, is provided by the neighbouring cantonal tumour registries of Vaud and Geneva (mostly upper aero-digestive tract, skin and childhood cancer cases) and the general practitioners.

Further information is also abstracted and systematically checked by the registry staff from hospital charts. A specificity and strength of the registry is the routine integration of an abstract of the medical record in the registry datafile and periodic computer linkage between the latter and the centralised cantonal administrative population database (active follow-up).

All death certificates are checked annually against the Registry files. This constitutes a process of passive follow-up, each subsequent item of information being used to complete the record of an already-registered case.

All relevant information is manually scrutinised before being interactively introduced into the computer of the Computer Center of Neuchatel. Additional, more sophisticated automated verifications and analyses are also performed on stored data in batch mode using *ad hoc* programs by the Vaud Cancer Registry on the computer of the University of Lausanne (UNIL).

Interpreting the results

There has been no organised screening during the incidence period for CI5-IX, but prescription of the PSA test is increasing, although not as dramatically as in most western European countries (preventive prostate examination—via biological test or clinical examination—reported on average by 15% of men aged 40–69 and resident in French-speaking Swiss cantons).

Use of the data

The registry provides routine statistical annual incidence and mortality data by sex, age and primary site, and data for local planning purposes. It is also engaged in (mostly) descriptive epidemiological studies in collaboration with the Vaud Cancer Registry and the six other Swiss population-based registries belonging to the Swiss Institute for Applied Cancer Research (SIAK).

Among the research opportunities offered by the operating structure within the collaboration agreement with the Registry of the Canton of Vaud is the definition of risk of second neoplasms for patients registered with a defined primary.

Source of population

Estimate: estimates from the Cantonal Office of Statistics; resident populations by sex and 5–year age group on December 31st. Sources: Office rne; Service Cantonal de Statistiques. Annuaires statistiques du canton de Neuchâtel, Neuchâtel, 1998–2002.

Multiple primary rules used

IACR rules (2004) on CI5 IX period.

Switzerland, St Gall-Appenzell

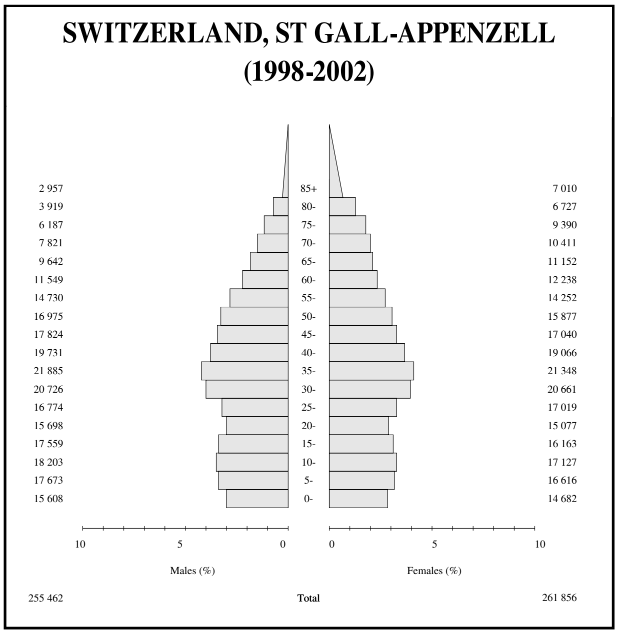
Registration area

The registry covers the three cantons of St Gall, Appenzell AR and Appenzell IR in the northeastern part of Switzerland, a total area of 2430km^2. It extends between latitudes 46° and 47° N; the lowest point is 396m and the highest 3247m above sea level.

The registry covers the entire resident population, amounting to 521 971 in mid-2002. Of this total, 87% belong to the canton of St Gall. Major parts of the area are rural. There is one city with 73 000 inhabitants. Important industries are metal machines and vehicles, and construction, which are relatively broadly distributed over much of the region. In 2000 the per capita income was 86% of the Swiss average in St Gall, 81% in Appenzell AR and 87% in Appenzell IR. Five sixths of the population are Swiss, the others mainly of other European origin.

Cancer care facilities

In 2002 there were 882 active physicians (1 per 592 inhabitants). About 1720 hospital beds were available in acute hospitals. The central hospital in the city of St Gall has a special clinic for oncology as well as for radio-oncology, and a public outpatient clinic for cancer patients that takes care of patients referred by general practitioners and other clinics. In addition, there are ten consultant oncologists. For inpatient care patients are usually referred to a hospital within their region. Most cancer patients are treated at the central hospital or in one of the peripheral acute hospitals within the region at least once during their disease. Some people in areas adjacent to the urbanised canton of Zurich seek care there.



Registry structure and methods

The cancer registry was founded by the Regional Cancer League in 1960 at the department of pathology in the central hospital of St Gall. It was hospital-based until 1980, when it became population-based. The sponsoring bodies are the Regional Cancer League and the three cantons covered by the registry, and it is also subsidised by the Federal Government. At present the registry has 3.6 full-time positions.

Reporting of cancer cases is voluntary. The most important data source is active and passive collection of reports from the central pathology laboratory. In addition, the registry staff actively collects data in the other pathology laboratories in the region and in all regional acute hospitals. In the central hospital, the departments of oncology, haematology, radiotherapy, neurosurgery, paediatrics and the geriatric clinic are actively scrutinised. There is a routine exchange of information with the other cancer registries of Switzerland, especially with those covering two neighbouring cantons (Zurich and Grisons). Active case ascertainment has also been organised with consultant oncologists in the region. Finally, all death certificates with a cancer diagnosis are scrutinised, and further information is sought out. Active follow-up for survival is carried out systematically at 5 and 10 years after diagnosis.

Reports are usually checked within a few days after receipt. Names and dates of birth are checked in order to find duplicates. In case of doubt, a physician is asked for advice. Six months after receipt of the first report, additional information is sought if necessary by mailed questionnaire or in the case notes of hospitals. Addresses are checked with official population control offices. Cases are finally coded and closed by a physician only about two years after onset.

Several logical checks are automatically made by the computer system. The coding is visually checked on the screen and, after completion of a case, on the case printout. Additional systematic checks on duplicate registrations are done after completion of a registration year. Checks on consistency of site, morphology and age are done through the Association of Swiss Cancer Registries.

Completeness of registration has been traditionally evaluated by the incidence/mortality method (death certificate method) and more recently via the so-called “flow method” (Boullard et al.). By this method it was ascertained that over 90% of the incident cases are registered within 12 months.

Interpreting the results

There are no population-based cancer screening programmes in this region. Screening is performed as an individual initiative and seems to be popular and effective for cervical cancer. More than 85% of cervical cancers registered were *in situ* carcinomas. Early detection of breast cancer, on the other hand, could be much improved. Only 7% of breast cancers registered in women aged 50–69 years during 2000–2004 were non-invasive.

Use of the data

The registry prepares yearly routine reports on cancer incidence including five-year periods. Analyses such as time trends of cancer incidence and mortality, survival and stage distribution in selected cancer sites are also carried out. *Ad hoc* analyses are done on request.

The registry’s data have been included in joint studies of the Association of Swiss Cancer Registries, e.g. on time trends of incidence of lung cancer, incidence of cancer in childhood, and the risk of cancer by occupation. The registry takes part in international studies (ACCIS, EUROCARE, CONCORD, EUROPREVAL, EUROCHIP) as well.

Source of population

Annual estimate of permanently resident population at mid–year, based on the 2000 census and taking into account births, deaths and migration. Source: Federal Office of Statistics, Switzerland.

Multiple primary rules used

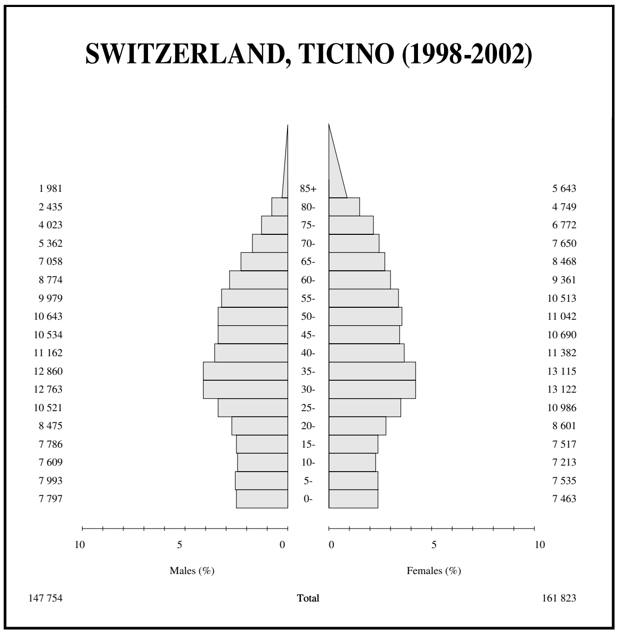
IACR rules (2004) on historical data.

Switzerland, Ticino

Registration area

The Canton of Ticino is situated at the extreme south of Switzerland. It has a total area of 2812 km^2 and is bordered on the north by the Canton of Uri, on the east by the Canton of Graubünden and Italy, and on the south and west by Italy. The highest point is 3402m and the lowest 194m above see level. The climate is temperate, with average temperatures varying from 4.0 in January to 21.8 in August, and the annual rainfall amounts to 1564mm (1997). Air quality has been measured in Ticino from 1990: the annual average pollutant concentrations observed are 13 μg/m3 for SO_2, 44 μg/m3 for NO_2 and 218 μg/m3 for O_3 (City of Lugano, 1996).

The population of the canton at 31 December 2000 was 309 357. The structure also reflects immigration in the age of economic activity: 73% of the population have Swiss nationality and 27% is foreign, mainly from Italy and the former Yugoslavia. The majority of the population is Christian, with 84% Roman Catholics. The official language is Italian. Employment distribution is: 1.7% in agriculture and forestry, 24.8% in industry and 71.8% in the service sector (census 2000).


SWITZERLAND, TICINO (1998-2002)

Cancer care facilities

In 2000, there were five public regional hospitals and four zone hospitals, for a total of 1042 beds and 695 hospital and private practitioners in the canton. There are no population-based screening programmes in Canton Ticino. Spontaneous screening is well accepted in the population, for either breast or cervical cancer. There is one radiotherapy department for the entire region covered by the Cancer Registry. Opportunistic PSA testing is common in the population.

Registry structure and methods

The Cancer Registry of Canton Ticino was founded in 1995 by the local government. Collection of population-based data began in 1996. The Cantone Ticino provides most of the budget and additional funds are obtained from the Federal Ministry of Health, through the Swiss Association of Cancer Registries.

The Registry was founded on a cantonal law, based on a popular initiative. It is located at the Cantonal Institut of Pathology. One medical doctor and a data manager are responsible for active data collection and coding. A statistician is responsible for quality control and data elaboration. Reporting of cancer cases is done on a voluntary basis. A web page is updated regularly (www.ti.ch/cancer). About 80% of cases are notified by the Cantonal Institute of Pathology and Cytology. Additional cases come from main hospitals, radiotherapy and oncology centres, haematology laboratory, oncologists, general practitioners and from cancer registries of Geneva, Vaud, Basel, Zürich and St Gallen (mostly skin cancer). Autopsy is performed on 3% of all deaths. Finally, death certificates with cancer diagnosis are scrutinised and additional information is found by mailing a questionnaire to the physician or by examining case notes in hospitals. Online control of inhabitants of the canton is performed at the Cantonal Office of Population Registry.

The Registry collects all malignant invasive and *in situ* tumours. The registration of basal-cell carcinoma is incomplete for the years 1996–2003. The following data are coded: personal identification number, tumour occurring before the registry was started personal data, date of first symptoms, date of morphology confirmation, topography, morphology, stage, diameter in mm and axillary node for breast cancer, basis of diagnosis, method of diagnosis, first treatment and date of death.

All information are manually checked and coded (according to ICD-O-2) by the registry staff before entry in the computer. The computers themselves do preliminary plausibility tests at data entry, and a second check is performed by the staff daily. Several plausibility checks, like logical sequence of dates, validity of codes, morphology by topography, by sex and age (over 200 crosschecks) are performed monthly in addition to the IARC Check programme.

Active follow-up of all patients with tumours is performed yearly. We have published a study of completeness: http://www.ti.ch/DSS/DSP/IstCP/RCT/pdf_ppt/Relazioni_e_Poster/2005/GRELL05_completeness.pdf.

Use of the data

The Registry is currently involved in epidemiological research such as biomolecular epidemiology, survival analysis (EUROCARE), and others:
http://www.ti.ch/DSS/DSP/IstCP/RCT/temi/studies.htm .

Policymakers use our Cancer Registry data for planning and evaluation of health services. Please see the website for further information: www.ti.ch/tumori.

Source of population

Average mid–year annual estimates, based on official numbers of births, deaths, immigrations and emigrations, on December 31st. Office cantonal de statistique.

Multiple primary rules used

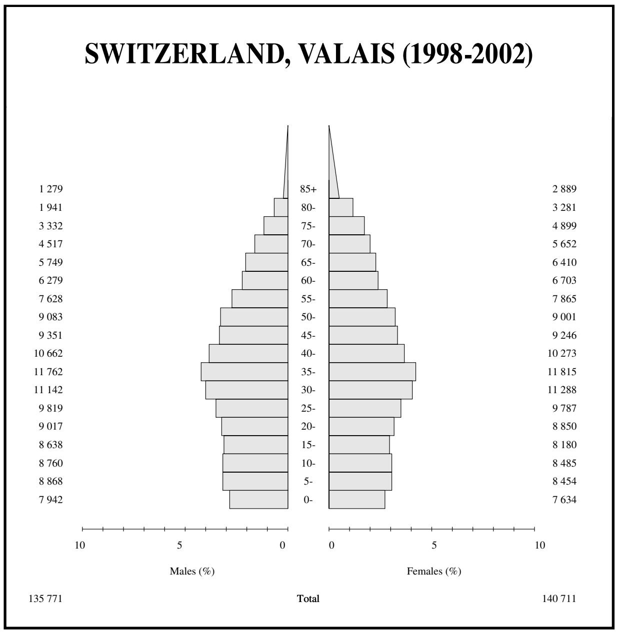
IACR rules (2004) on CI5 IX period.

Switzerland, Valais

Registration area

The canton of Valais covers an area of 5225 km^2, with a population of 281 500 at the end of 2002. The population is 35% urban, the majority living in a rural area or in the mountainous region of the Alpine range. The Valais Alps, a non-productive area, account for 54% of the land surface. The climate is relatively drier and sunnier than in the rest of northern Switzerland. The German-speaking ‘High’ Valais, 28% of the canton, is distinguished from French-speaking Central Valais and ‘Low’ Valais not only by language, but also by culture.

The population is largely of Caucasian origin; the majority are Roman Catholics (81%). The population is 17.6% of foreign origin, principally Italian Portuguese and people from the former Yugoslavia. The structure is that of an ageing population, with 15.6% of people older than 65 years. One of the features of this population is its great stability, the genetic structure being more homogeneous than is general in the country—a fact demonstrated by the studies on genetic predisposition to colorectal cancer.


SWITZERLAND, VALAIS (1998-2002)

The economically active population works 58.5% in the services and tourism sector, 22.5% in industry (construction, chemical, metallurgical, wood) and 3.5% in agriculture. Valais is an important producer of wine (40% of the national total), fruit and vegetables. From the viewpoint of potential occupational risk factors, there are three industrial centres, each with more than 1000 employees, producing plastics, colorants, agrochemical products, aluminium (exposure to fluorine and asbestos), solvents and products derived from cyanide.

Cancer care facilities

There are 19 physicians per 10 000 inhabitants. The health system centres around six public hospitals, a specialist respiratory centre and one private clinic, a total of 840 beds for acute care, excluding several geriatric, psychiatric and chronic care institutions. The Department of Oncology of Valais is a network of cancer care facilities which gather specialists consulting in the public hospitals and in private, or working in a centralised radiotherapy service in Sion. A few cases requiring additional facilities are treated in university centres such as Lausanne, Geneva, Berne, Zurich or Basel.

Registry structure and methods

Since 2002, the registry has been attached administratively to a newly created ‘Health Observatory’ of Valais, supervised by the Public Health Service of the canton and situated in the capital Sion. The registry is located there and shares the computer network of the Central Institute of Valais Hospitals (CIVH). The registry is largely financed by the Canton of Valais; the Swiss Confederation contributes 10–15% of the budget.

The staff consists of a physician responsible for registration (80% of one post), an assistant physician (40% of one post) and two secretaries (one post full-time, one half-time).

The principal source is the pathology department of the CIVH, whose histological or cytological reports concerning cancer are available to the registry via specific software. This source represents about 75% of the cases registered. Other sources comprise registries situated in the university centres of other cantons, the medical records of the hospitals (notifications are made on the basis of computerised lists of hospitalisation with diagnoses coded to the ICD), oncological specialists who send a copy of their consultation reports, and a computerised listing of deaths.

Notification is essentially passive, but a questionnaire is sent to the treating physician for the majority of registered cases, and demographic data are verified through the municipalities, again by questionnaire.

Access to death certificates is authorised for DCN cases through a contract with the Federal Office of Statistics, Neuchâtel, thus guaranteeing confidentiality.

Notification of cancer is voluntary. Physicians are authorised to transmit data if their patient has not specifically refused such communication, which had never happened by the end of 2002. In 1995 an expert commission on professional secrecy and medical research authorised regulations for medical confidentiality throughout the process of data collection, storage and processing of data.

The data are validated by different programs, including IARC Check. Quality control of data notified electronically is carried out by the suppliers.

Interpreting the results

Most demographic factors have remained stable. The increasing percentage of foreigners since 2000 is due partly to a renewal of immigration and a more constant birth rate in the native population.

Use of the data

The incidence data are used to inform the public health planners and the medical profession about cancer in the population. The results of the most recent reports have confirmed discrepancies between the incidence of some tumours in two different regions, i.e. ‘High’ Valais and ‘Low’ Valais. In particular, lung cancer is more frequent in the western (‘lower’) part than in the eastern, German-speaking ('higher') part of canton Valais. The intensification of cancer screening (an official breast cancer screening programme for women aged 50–70 started in autumn 1999) has contributed to an increase in the incidence of breast cancer mainly and prostate cancer secondarily. The registry also participates in survival studies at the national (Association of Swiss Cancer Registries) and international levels (CONCORD study).

Source of population
Annual estimate of permanently resident population at mid–year, based on the 2000 census and taking into account births, deaths and migration.
Source: Federal Office of Statistics, Switzerland.

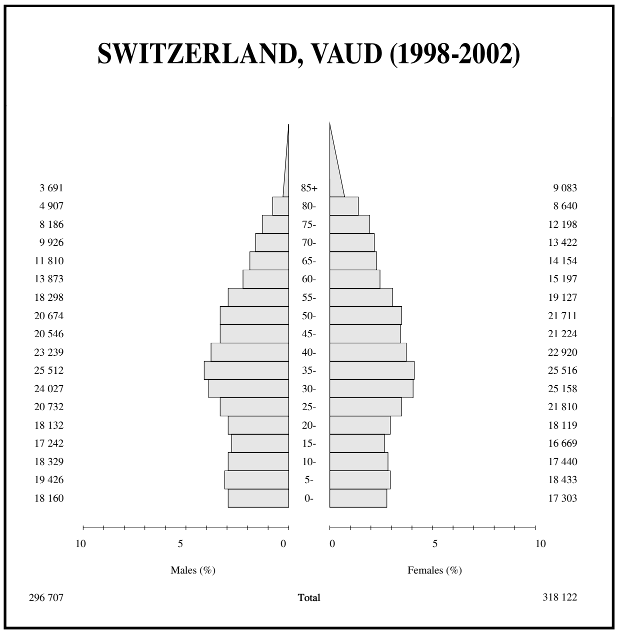
Multiple primary rules used
IACR rules (2004) on historical data.

Switzerland, Vaud

Registration area

The registry covers the French-speaking Canton of Vaud, the fourth-largest of the 26 cantons in the Swiss Confederation (surface area 3212 km^2) and third in number of inhabitants (about 640 000 in 2000).

The 385 communes that compose the canton are grouped into 19 administrative and political districts. The density of population (193/km^2) slightly exceeds the mean for the whole country. In 2000, foreigners, predominantly of Mediterranean origin, accounted for about 25% of residents. Since the early 1970s the number of resident workers has remained stable. In 2000, the main occupations were industry (19%), agriculture and fishing (5%) and services (76%). In December 2000, only 23% of the Vaud population were 0–19 years old, while 15% were aged 65 years and older. Although Lausanne, the capital and its suburbs represent only 4% (115 km^2) of the canton's area, about 45% of the total population reside there.



Cancer care facilities

In 2000, about 3000 public and private hospital beds (about five hospital beds per 1000 population) were available for diagnosis and treatment. In the same year there were about 2800 hospital medical doctors and private practitioners (one per 230 population). The health care system is insurance-based, but practically the whole of the population enjoys access to medical care. A major public university multi-disciplinary oncology and radiotherapy (1142 treatments in 2003) centre is available to the whole population, as well as a few peripheral—mostly hospital-based—medical and surgical oncological facilities. Two additional radiotherapy private units are in operation (overall, 948 treatments in 2003).

Registry structure and methods

The Registre Vaudois des Tumeurs (RVT) began in January 1972, and population-based data have been available since 1974. The registry is a constituent part of the Cancer Epidemiology Unit at the Social and Preventive Medicine Institute (IUMSP), University of Lausanne. The majority of the financial support comes from the Public Health Department of the Canton of Vaud. Additional *ad hoc* funds are supplied by the Swiss Federal Government and the Swiss League against Cancer, which support several studies in the fields of descriptive and analytical epidemiology.

In addition to the director, the staff comprises one part-time medical associate, one part-time computer programmer, and 3.5 clerks. The director is also in charge of the administrative and scientific supervision of the cantonal Registry of Neuchatel.

Notification is based on a voluntary agreement between the recording medical institutions of the canton and the registry. The main sources are the cantonal University Pathology Department of Lausanne and three other major private pathology laboratories, which perform the majority of the histological examinations for the population. Most cases are registered repeatedly and from different institutions. Cancer cases are listed alphabetically and according to a chronological registration numerical index.

All relevant information is checked manually by the registry staff and subsequently coded before being entered into the computer of the University Hospital of Lausanne (CHUV). A first series of automatic checks on data is run whenever new information or modifications are added. Data are transferred to the computer of the University of Lausanne (UNIL), where more specialised checks and analyses are performed. Passive and active follow-up information is recorded. Identification data on all deaths in the Canton of Vaud as well as on cancer deaths are available.

Interpreting the results

A mammography screening programme for breast cancer was activated in 1999 targeting all resident (about 70 000) women aged 50–69 (participation rate around 50% in 2003). Spontaneous screening for cervical cancer is common (over two thirds of women aged 20 or older report at least one examination). According to the most recent National Health Survey, on average 15% of men aged 40–69 and residing in the French-speaking cantons (Suisse Romande) reported a biological test or clinical examination of the prostate within the year preceding the survey.

Use of the data

Annual incidence data by sex, age, site and morphology are routinely provided. The registry is also engaged in both descriptive and analytical research in the field of epidemiology. Features of the registry include good registration of non-melanoma skin, since traditionally the large majority of cutaneous lesions are surgically resected and examined by a pathologist, linkage of selected pre-neoplastic conditions to the cancer registry datafile in order to study subsequent cancer risk, risk of second neoplasms for patients registered with a defined primary, and systematic analyses of trends in survival. The registry cooperates with clinicians, and is used for population-based case–control studies on ENT, colorectal, breast, endometrial and thyroid cancers. It also serves to evaluate the three breast cancer screening programmes run in the Cantons of Vaud, Wallis and Jura.

Source of population

Average mid–year annual 1998–2002. Estimate: Cantonal Office of Statistics (SCRIS) for each calendar year and five–year age group, based on official numbers of births, deaths, immigrations and emigrations, on December 31st.

Multiple primary rules used

IACR rules (2004) on CI5 IX period.

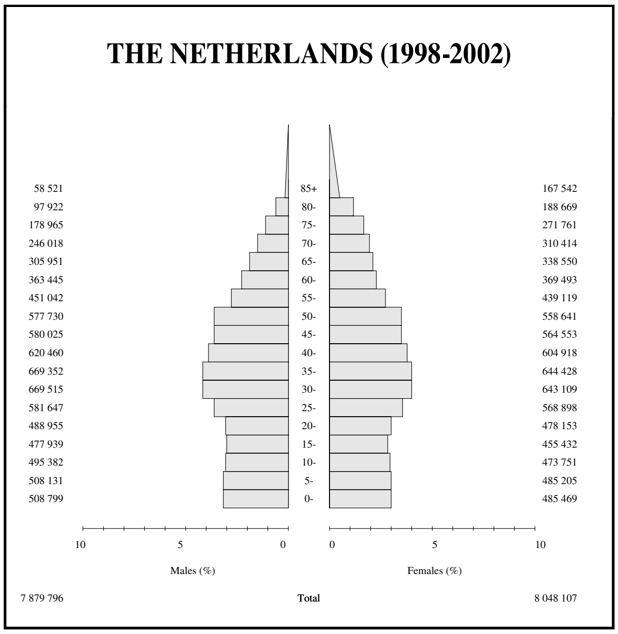
The Netherlands

Registration area

The Netherlands Cancer Registry (NCR) comprises nine regional cancer registries and covers the whole population of the Netherlands. The population in 2007 was 16.3 million.

Comprehensive Cancer Centres

General health care in the Netherlands is provided by general practitioners and specialists in academic (7), oncological (2) and general hospitals (5–20 hospitals per region). At least one radiotherapy institution is situated in every region. The nine Comprehensive Cancer Centres (CCC), which are partnerships between healthcare professionals and cancer and palliative care institutions, together form the Association of Comprehensive Cancer Centres). The purpose is to provide access to comprehensive and high-quality care as close to home as possible. The CCCs support networks of specialists and tumour-specific working groups with the development, implementation and evaluation of national and regional guidelines. Consultants are supported for several specialties. Patients in need of specialist care can be referred out of their CCC region. More than 300 employees work in these CCCs, and about 400 consultants are actively involved. CCC,s are independent, private institutions and all hospitals, radiological centres and pathology labs are affiliated with one of the nine centres.



The CCCs receive a fixed annual sum for staffing, materials and location costs, and a variable amount to cover the costs of consultants funded according to the policy regulations of the National Health Tariffs Authority on the basis of the National Health Tariffs Act. In addition, grants are obtained from various bodies including the Dutch Cancer Society (used for activities such as the support of clinical trials), the Ministry of Health, Welfare and Sport (for developing guidelines) and from other organisations (for projects).

Registry structure and methods

The nine regional Cancer Registries, located within the CCCs, pool their data once a year in the NCR. Cancer registration is funded according to the policy regulations of the National Health Tariffs Authority on the basis of the National Health Tariffs Act.

The main source of data is the pathological automated archive (PALGA). Notification also comes from radiotherapy centres and haematology labs, and once a year the cancer registry is linked with the Hospital Discharge Register, which accounts for about 8% of the registered cases. Death certificates are not available because of privacy regulations. Specially trained registration clerks register direct from the medical records in the hospitals.

Interpreting the results

The Netherlands Cancer Registry has been population-based since 1989 and is more than 95% complete. Patients with “cancer” only on their death certificate will be missed, as will cases that have no pathology, cytology or hospital intake.

Use of the data

The registry prepares an annual report of cancer incidence, highlighting trends and changes on both national and regional level. Data are linked with the breast cancer screening programme for evaluation purposes. Several projects (e.g. guideline evaluation and evaluation of the National Cancer Control Plan) with hospitals and universities are supported by cancer registry data. More than 25 data requests are answered every year, both at the national and regional levels.

Source of population

Statistics Netherlands.

Multiple primary rules used

IACR rules (2004) on CI5 IX period.

Notes on the data

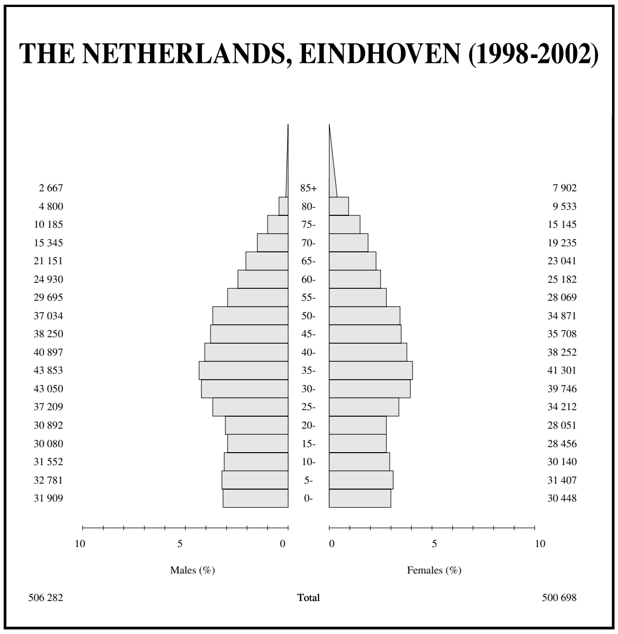
C67 does not include non–invasive tumours.

The Netherlands, Eindhoven

Registration Area

Since 1972 the registry has served an area of about 2500 km^2, lying 20–50m above sea level and including almost one million inhabitants (6% of the 1990 Dutch population). Since 1988 another million have been added bringing the total 2000 population to 2.3m and being part of the national registry. This dataset only includes incidence and mortality data from the original population that grew from almost 300 000 since 1958. The population density was about 400 per km^2, roughly the national average; 47% of the population-at-risk live in urban, 43% in suburban and 10% in rural municipalities. The traditionally Catholic population has secularised rapidly since the mid-1960s, with concurrent large-scale introduction of oral contraceptives leading to a lower fertility rate (from 3 to 1.5) and higher age at first birth (from 22 to 29 years). The proportion of immigrants has been rapidly rising since the 1970s, to >10% at younger and middle age.

With regard to the environment, an intensive pig and poultry breeding industry has developed since the 1970s, contributing considerably to acid rain and rising nitrate levels in groundwater, decreasing again since the 90s. The main industries produce electronic goods, trucks, photocopiers, textiles and milk products, but increasingly replaced by employment in services and transport. The declining tobacco-processing and cigar industry, important in the south-of-Eindhoven area until the 1980s, had a marked effect on the incidence of lung cancer among males, whose prevalence of smoking was 95% in the 1950s. By contrast, smoking prevalence and incidence of smoking-related cancers among females have only risen rapidly since the mid-60s. Among those born after 1965 incidence appears to have begun decreasing again.



Cancer care facilities

In 2004 we began a national obligatory insurance system. Some 98% of the inhabitants are covered by Sickness Benefit Funds, a compulsory social insurance policy for people with low income; less than 1% of the population may be uninsured.

The growing interest in oncology during the 1970s led in 1979 to a regional organisation, the Cooperating Association of Hospitals in Oncology (SOOZ). In 1982 the Comprehensive Cancer Centre South (IKZ) was founded as a collaborative effort of the radiotherapy institutes in Eindhoven and Tilburg and 18 community hospitals, one of its main tasks being cancer registration.

Access to clinical specialists was good but deteriorated a bit until 2000, generally through general practitioners, one for every 2200 persons. Despite a markedly ageing population the number of hospital beds decreased from 5 to 2.0 per 1000 persons in the past 25 years, while the number of nursing home beds has increased, as has, more recently, home care provision. In the late 1990s, hospitals halved in number by mergers to only middle- and large-sized hospitals from 400 to 800 beds.

Registry structure and methods

This regional registry began operation in 1955 as part of a programme for nationwide cancer registration. The 13 participating hospitals of the 1970s have now been merged into 6. The registry has always cooperated systematically with up to three regional pathology laboratories, which have paraffin-embedded blocks of biopsy specimens from all patients since the 1970s. These laboratories also serve GPs. Moreover, through the various medical records departments the registry has access to the medical records of most hospitals, in particular in the department of Radiotherapy in Eindhoven, which has gradually extended service to all of these hospitals. Since 1988 the registry has functioned within the scope of a national scheme for cancer registration, developed since 1984. Assessment of completeness and accuracy was carried out in the period 1980–83 with continuing support from the Department of Epidemiology, now Public Health, of Erasmus University, Rotterdam. Extensive analyses of incidence since 1958 thus became possible, e.g. for lung and breast cancer, both of which exhibited major changes. Such data have now been submitted to Cancer Incidence in Five Continents since 1958 and EUROCIM since the early 80s. They include—in a large part of the area—non-melanoma skin cancer, based on early involvement of also dermatologists.

Using the municipal population registers, active follow-up with respect to vital status was performed in 1987, 1991, 1994, 1999, 2002 and 2006. Patients lost to follow-up declined from 5% to less than 1%, with regular aid from the Central Bureau of Genealogy.

Interpreting the results

Screening for cervical cancer, started during the 1970s but declining in the 1980s, started again in 1988, being adapted in 1996 among women 30–60 years of age at 5-year intervals. Biannual mass mammography screening for breast cancer gradually started among women between 50 and 70 years during 1992–96, rising to age 75 in 1998.

Use of the data

Regular overviews of trends in incidence, stage and survival of patients registered since 1958 are published every five years, including detailed information on uncommon tumours and prevalence since 1970 and co-morbidity at diagnosis since 1993. Cancer survival has also been studied since 1978 within the framework of the EUROCARE study.

In recent years the data have been used increasingly for quality-of-care purposes and studies of cancer in the elderly; for that purpose, serious co-morbidity at diagnosis was also registered and a research department developed with a strong regional, national and European orientation.

Source of population

Population data are calculated annually for 1 January; they are derived by Statistics Netherlands from the municipal population registries.

Multiple primary rules used

IACR rules (2004) on historical data.

The Netherlands, Maastricht

Registration area

The Maastricht Cancer Registry is situated in the southeastern part of The Netherlands, and comprises the southern and middle parts of the province of Limburg, an area of some 1355 km^2. A large area to the west, south and east is bordered by Belgium and Germany. The Eindhoven Cancer Registry is on the northern boundary.

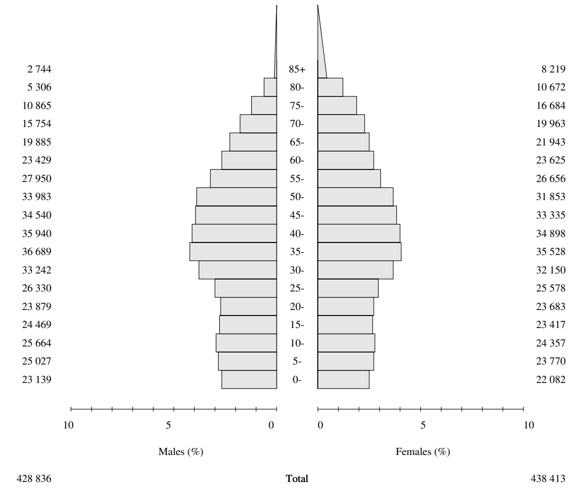
In the southern part of Limburg, the population density is very high, with about 30% of the population living in rural municipalities, 57% in sparsely and moderately urbanised municipalities and 14% in densely urbanised municipalities.

Current industrial activities in the region include chemical, automobile, ceramic and cement industries. Until 1975, coal mining was a very important source of employment.

The vast majority of the Limburg population is Catholic.

Cancer care facilities

There is easy access to medical care in the Netherlands. In the province of Limburg there is about one general practitioner (GP) per 2300 inhabitants. Medical specialists usually work at the hospitals: they can be consulted after referral by the GP. Due to the ageing population, cancer care facilities will be consulted more frequently in the future. Almost all cancer patients are diagnosed and treated by medical specialists. In the area of the Maastricht Cancer Registry, there are four general hospitals and one university hospital. The area also has one radiotherapy institute.


THE NETHERLANDS, MAASTRICHT (1998-2002)

Registry structure and methods

The Maastricht Cancer Registry was established in 1984 as part of the Comprehensive Cancer Centre (CCC) Limburg. Within CCC, there is collaboration between the hospitals, Maastricht University and the Maastro Clinic (radiotherapy institute). The aim of the CCC is to improve care for cancer patients through research, treatment, guidelines and coordination of regional activities (e.g. cancer screening).

The Maastricht Cancer Registry (MCR) is part of the nine regional cancer registries in the Netherlands. Together these registries make up the Netherlands Cancer Registry. The staff of the registry includes one epidemiologist as head of the registry, two epidemiological researchers, one computer programmer and six tumour registrars. In addition, one consultant on cancer registration is available.

Notification is voluntary. The cancer registry receives lists of newly diagnosed cases on a regular basis from the four pathology departments in the region. In addition, the medical records departments of the five hospitals provide lists of hospitalised cancer patients. Following notification, the medical records of newly diagnosed patients are collected and trained tumour registrars for the cancer registry abstract the necessary information from them.

Death certificates cannot be used because of the privacy regulations of the Dutch Central Bureau of Statistics. Tumour data are copied onto registration forms at the hospitals and entered into the computer at the registration office. Completeness of records, data consistency and the possibility of duplicate records are continuously and extensively checked by the computer program.

Interpreting the results

Research into the completeness of ascertainment and into the validity and accuracy of data show that the quality of the data is high (Int J Epid 1993;22:369-76, Br J Cancer 1993; 68:947-77, Int J Epid 1994 23;1111-6).

In 1990 a breast cancer screening programme started, resulting in a large increase in the incidence of breast cancer. A cervical cancer screening program started in 1992 and expanded to the whole region in 1996 for women aged 30–60. Trends in prostate cancer incidence also show a large increase, associated with opportunistic PSA screening.

Use of the data

The registry regularly publishes a report on cancer incidence. Data for the Maastricht Cancer Registry have been used for etiological research, evaluation of guidelines, evaluation of screening programmes and the treatment of cancer in the elderly. The data are also used to plan healthcare facilities.

Source of population

Statistics Netherlands.

Multiple primary rules used

IACR rules (2004) on historical data.

UK, England, East of England Region

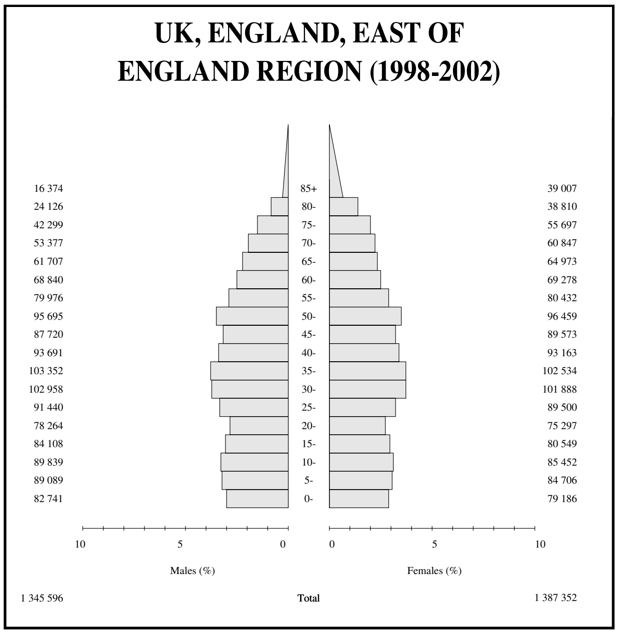
Registration area

ECRIC registers cancers occurring in the resident population of Norfolk, Suffolk, Cambridgeshire and, since 1996, Bedfordshire. It is situated in eastern England UK with a population (at the most recent census) of 2.75 million; 90% of the population describe themselves as white British.

In 1995 the registry assumed responsibility for the resident population of Bedfordshire, and in 2006 responsibility for Hertfordshire and Essex was added. As a result of this, the population covered increased from approximately 2.2 million to 2.6 million in 1995, and from 2.8 million to 5.3 million in 2006.

Cancer care facilities

The registry is situated in Addenbrooke's NHS Trust Hospital in Cambridge, with 2 satellite offices in The Norfolk and Norwich University Hospital in Norwich and the Ipswich Hospital. Each of them has radiotherapy, oncology and surgical facilities. There are 6 other hospitals in the region providing oncology services. Some patients are sent out of the area to receive radiotherapy treatment at Mount Vernon Hospital, Northwood, Middlesex.


UK, ENGLAND, EAST OF ENGLAND REGION (1998-2002)

Registry structure and methods

The registry is funded by the government Department of Health under the Public Health budget. There are 24 staff as follows: Director, operations manager, consultant oncologist, two senior registration officers, 11 registration officers, two clerical officers and three workers each in analysis/quality assurance and IT.

Registry staff extract data from patient's notes and hospital PAS systems at all the hospitals in the region. Data are recorded on paper forms and later transferred to a computer database when complete.

A monthly updated "snapshot" of the database is produced using Microsoft Access for the analysis team to interrogate to produce reports and answer specific queries from external sources.

A detailed formal evaluation of Annual Performance Indicators is already carried out according to the guidelines established by the UKACR.

Interpreting the results

PSA testing is quite common, and parts of the registry population are included in a large-scale study evaluating screening for prostate cancer.

Multiple primary rules used

IACR rules (2004) on historical data.

UK, England, Merseyside and Cheshire

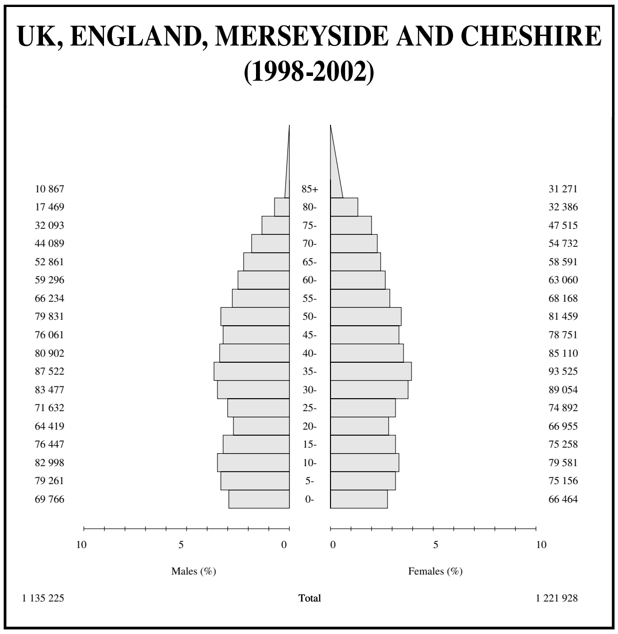
Registration area

Since 1974, the registry has collected data on all cancers occurring in residents of Merseyside and Cheshire, wherever treated, and on residents of other areas treated in Merseyside and Cheshire hospitals. The registry also collects data on Isle of Man residents.

Population centres in the area include the city of Liverpool; industrial towns such as Birkenhead (previously shipbuilding), Runcorn (chemicals), St Helens (glass); the retirement coastal town of Southport; and the rural towns of Cheshire.

Cancer care facilities

Local Cancer Services have been reorganised into networks with a specialist cancer centre (containing full radiotherapy and oncology facilities) and cancer units in a "hub and spoke" arrangement to achieve the most effective concentration of expertise and also obtain the closer involvement of primary care.


UK, ENGLAND, MERSEYSIDE AND CHESHIRE (1998-2002)

Registry structure and methods

The registry was founded in 1944 as the Liverpool Clinical Cancer Registry, with the primary objective of registering all cases of malignancy occurring in the area served by the Liverpool Radium Institute. It extended its coverage to the surrounding area in 1974. The registry is part of the National Health Service.

Registry staff comprise: a medical director, a general manager, two deputy managers, an epidemiologist, a secretary, a quality assurance officer, an IM&T officer, an intelligence officer, 6 registration officers and a database specialist. In addition, project work is undertaken by students studying for higher degrees and professional examinations.

The most important source of notification is pathology reports, copies of which are routinely sent to the registry. All cases are followed up by trained registration officers, who abstract relevant clinical information from hospital records. Notifications are also received from the Office for National Statistics about death certificates for people who have died of cancer. Full registration for these cases is then sought by Merseyside and Cheshire Cancer Registry from the hospital or certifying doctor. The local specialist centres for oncology also supply notifications. Details of Merseyside and Cheshire residents whose cancers are diagnosed elsewhere are supplied by the local registry. Cases registered during life are flagged at the National Health Service Central Register so that the cancer registry is informed when these cases die.

Registry data are held on a dedicated relational person-based system. Each tumour is allocated a unique tumour number in addition to the patient's unique identifier. Validation checks within the system were extended in 1994 to improve the quality of data inputting. The registry has a rolling programme of quality assurance focussing on the ascertainment, completeness, timeliness and "housekeeping", and several projects have explored different aspects of data quality. Data are coded in ICD-0-2, kept securely and released in a controlled manner, in accordance with ethical and data protection conventions. Regular backups are taken of the data and kept both locally and off-site.

Interpreting the results

There have been no coding or registration practice changes that affect the interpretation of the data in this report compared with earlier volumes.

Organised screening programmes are in place for breast and cervical tumours. In 1988 a national breast screening programme was introduced, through women aged 50–64 years are routinely invited to be screened for breast cancer every three years; women above 64 years are screened if they, or their general practitioners, request a test. A similar screening programme for cervical cancer was introduced in 1964, whereby all women aged 20-64 are screened, currently every three to five years, depending on their primary care trust and their age.

The increasing use of opportunistic PSA testing within Merseyside and Cheshire coincides with an increase in the number of prostate cancer cases registered locally.

Use of the data

Publications include specialist reports on breast cancer (2003), colon cancer (2003) and oesophageal cancer (2003).

Other output includes responding to over 80 ad hoc queries annually; presentations concerned with place of death and also cervical screening age; audits with specialist researchers; responding to genetic counselling service enquiries; contributions to the regional public health report; analyses to support the planning of local cancer services; and regular presentations to specialist groups.

Source of population

Estimation of population at risk based on 2001 census, allowing for births and deaths and migration into and out of the area.

Multiple primary rules used

IACR rules (2004) on historical data.

Notes on the data

C44 not available.

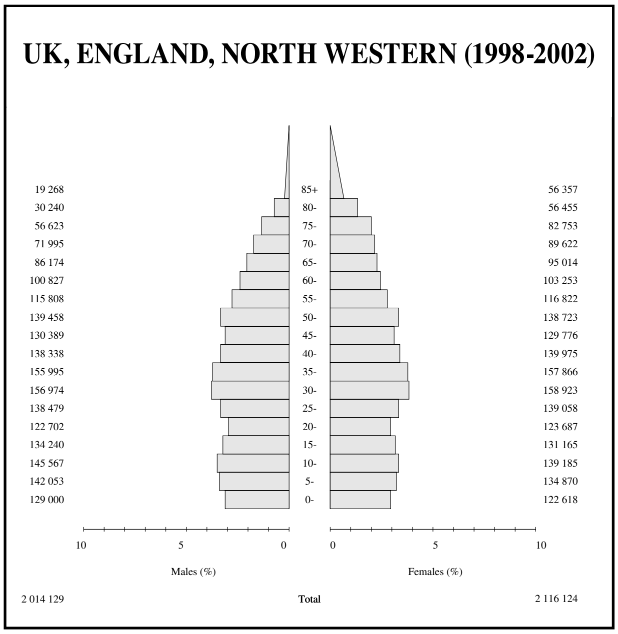
UK, England, North Western

Registration area

The North Western Cancer Registry (NWCR) collects data on all residents of Greater Manchester, Lancashire, South Cumbria and a small part of Derbyshire who develop cancer. The Registry covers an area of 4500km^2 and has a population of four million. Sixty-five percent of the population resides in the conurbation of Greater Manchester, which is almost entirely urban. The remainder of the region is of mixed urban-industrial and rural character. Eleven percent of the population lives in areas adjoining the coast, which are characterised by a high proportion of elderly retired residents. Ethnic minority groups comprise almost 8% of the North West population, concentrated mainly in large cities.

Cancer care facilities

Local cancer care services are being reorganised into networks with a specialist cancer centre (containing full radiotherapy and oncology facilities) and cancer units in a ‘hub and spoke’ arrangement to achieve the most effective concentration of expertise and obtain closer involvement of primary care.



UK, ENGLAND, NORTH WESTERN (1998-2002)

Registry structure and methods

The NWCR was founded in 1962. It is situated at the Christie Hospital, the principal cancer centre serving the Region.

Registry staff comprise a medical director, office manager, systems manager, epidemiologist, information manager, systems analyst, deputy manager, quality assurance officer, one secretary, and eight cancer registration officers.

The vast majority of patients receive their hospital care in the National Health Service hospitals. All NHS and private hospitals use special form to notify the Registry of all cases of cancer diagnosed in patients admitted to their hospital. The registries of other regions notify the Registry of residents of the region who are treated in hospitals outside the region. The Registry also receives data from hospital information systems. The Registry has links with all pathology laboratories in the region so that copies of pathology reports can be sent directly to the Registry. The Registry receives copies of death certificates of all regional residents whose certificate mentions cancer. The Registry collects further information on patients identified only by a death certificate.

Cases are followed up through the statutory registration of deaths. All patients are flagged at the National Health Service Central Register and the Office for National Statistics informs the Registry of patients who have been previously flagged as having developed cancer.

All addresses are assigned post-codes, and all information is computerised and submitted to validation and consistency checks. Diagnostic details are entered on the computer, which then automatically codes them to ICD-O. Validation checks within the system were extended in 1994 to improve the quality of data input.

Interpreting the results

There have been no coding or registration practice changes that affect the interpretation of the data in this report compared with earlier volumes.

Use of the data

A number of reports have been published examining variations in cancer incidence and survival in the population covered by the Registry. A joint report with the Merseyside and Cheshire Cancer Registry (MCCR) covering the whole of the North West Region has been published. Registry data are used to plan and evaluate cancer services, including the breast and cervical screening programmes. A number of audits using Registry data have been undertaken. Several research studies, both national and international have used Registry data. In addition, Registry staff have collaborated on several studies on a range of topics, including the genetics of breast cancer and the reasons why women with bladder cancer have a worse prognosis than men.

Source of population

Source: 2001 Census, Office for National Statistics.

Multiple primary rules used

IACR rules (2004) on historical data.

Notes on the data

C44 not available.

UK, England, Northern & Yorkshire

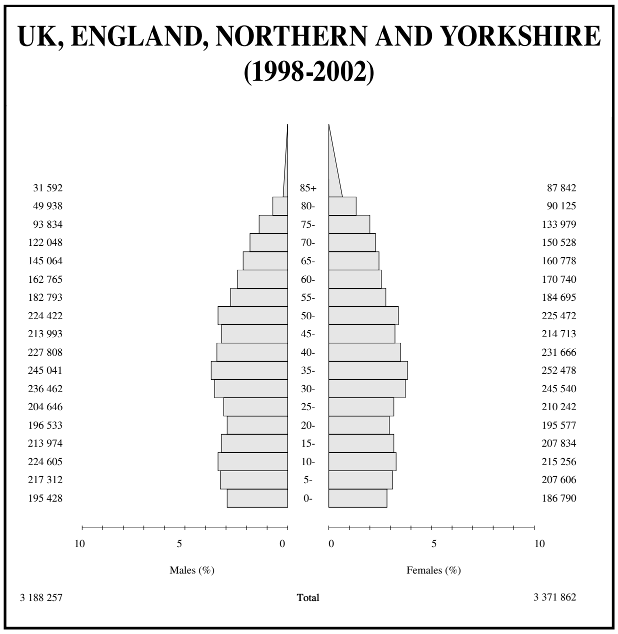
Registration area

The area covered by NYCRIS (Northern and Yorkshire Cancer Registry and Information Service) is a little under 30 000 km^2, and includes much of the North of England: from North Cumbria to Northumberland (Scottish border), down to West Yorkshire (east of the Pennines) and across to Humberside and the North Lincolnshire Coast.

The region comprises the large rural expanses of the Northern Lake District, Northumberland, County Durham, West, East and North Yorkshire. Within these are several densely populated urban clusters, including Tyne & Wear/Teesside, Leeds/Bradford, Huddersfield/Calderdale and Humberside, along with some smaller (formerly fortified) cities, such as York, Durham and Carlisle. Health geography, for 1998–2002, maps the area directly to four Cancer Networks or 44 Primary Care Trusts (PCTs).

Total population is around 6.7 million (at 2001 census), which constitutes 12.4% of the population of England & Wales. There is marked variation in population density across the region, varying from 0 to over 2500 people/km^2 in Hull & Stockton-on-Tees (www.statistics.gov.uk/regionalsnapshot/). Ethnic groups include Black 0.4%, Asian 3.4%, and Other 0.4% (% of total population, 2001 census).

The age structure is not significantly different from that of England and Wales as a whole, although the percentage aged 25–35 years is slightly higher.


UK, ENGLAND, NORTHERN AND YORKSHIRE (1998-2002)

Traditional industries include shipping, fishing, textile & clothing manufacture, steel production, shipbuilding and coal mining.

Cancer care facilities

The vast majority of patients receive their hospital care in National Health Service (NHS) hospitals. A major national reorganisation of cancer services has taken place since 1995, following the report of an Expert Advisory Group on Cancer to the Chief Medical Officers of England and Wales. The subsequent National Cancer Plan (2000) established a system of Cancer Networks each serving populations of 1–3 million and organising specialist cancer care through multidisciplinary teams. There are four such networks in the NYCRIS region, based around hospitals in Newcastle, Middlesbrough, Leeds and Hull, which, together with their associated local units in smaller district hospitals, provide integrated cancer services for their populations. The hospitals within these 4 cities are the cancer treatment centres; there are radiotherapy departments located proximate to the treatment centres.

Registry structure and methods

NYCRIS was set up in 1997 to integrate the two separate regional cancer registries of Northern and Yorkshire. Due to the quality of pre-1998 Northern data, only Yorkshire cases have been included in earlier volumes of CI-5.

NYCRIS is based in Leeds, adjacent to Cookridge Hospital, which is part of Leeds Cancer Centre. It currently employs around 50 staff, of whom approximately 60% are involved in data collection and validation (for the whole of the Northern and Yorkshire area), 15% in data management/quality assurance and 15% in information and research.

Cancer registration in the UK is mandatory, and cases diagnosed in hospitals (inpatient and outpatient) are notified directly to NYCRIS. All pathology laboratories throughout the region routinely send copies of pathology reports, and these act as a cross-reference to information received directly. Northern & Yorkshire residents treated outside the region are notified by other cancer registries. Notification also comes from Breast Screening Units and hospices. Cases are registered by registry staff who visit the hospitals and abstract treatment details from hospital case notes following primary notification. Copies of death certificates are routinely received from National Statistics for all cases where cancer is a cause of death. When this information is the first notification of cancer, the registry traces the death to search for further information. When the cause of death is non-malignant, the registry is notified by the National Health Service Central Register, where all registered cancer patients are flagged.

A new registration system (PRAXIS) was implemented in 2006 to enable NYCRIS to move from the current, largely manual, cancer registration process to one making greater use of electronic data feeds. The cancer registry database is patient-based. Records of existing registrations are updated with new information, new cases being assigned an accession number by the computer. All data items are encoded by the computer. The system also automatically generates a general practitioner's enquiry letter, a cancer registration document and a follow-up enquiry letter where necessary. At the point of entry, data are validated using the National Statistics edit procedures. Data are regularly exchanged with local specialist tumour registers to ensure complete ascertainment.

Use of the data

In addition to providing a responsive information service, NYCRIS regularly produces data and reports in a variety of media and actively promotes the use of its data. Summary statistical information (incidence, mortality and survival) is contained in CIS (Cancer Information Service), a web-based analytical tool available over NHSnet (protected health service WAN).

Details of CIS and all of its published reports are available on its web site (www.nycris.org.uk). In addition NYCRIS has conducted a series of regional audit reports, on important issues related to cancer service delivery; for example, analysis of variation in the patterns of cancer care and the effect of such variation on survival, an examination of methods to improve the registration of skin cancer and analyses of patient waiting times before receiving treatment.

Source of population
UKACR Populations Dataset Version 3.

Multiple primary rules used
IACR rules (2004) on CI5 IX periods.

UK, England, Oxford Region

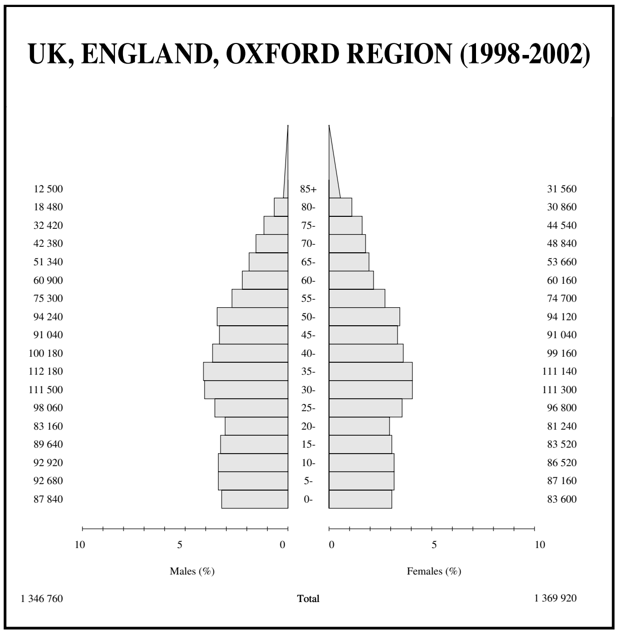
Registration area

The Oxford region consists of the counties of Berkshire, Buckinghamshire, Northamptonshire and Oxfordshire, and covers a population of about 2.7 million people. There are slightly more females than males (51%/49%). During the last 20 years higher population growth has been experienced within major urban areas.

Berkshire has the highest population with 800 100 residents, Buckinghamshire has 686 100, Oxfordshire has 605 500 and Northamptonshire 629 700. Oxfordshire has the highest proportion of elderly residents, with 14.5% being 65 or over. Northamptonshire has 14.2% of over-65s, Buckinghamshire has 13.3% and Berkshire 12.7%. Around 13% of the population are aged under 10, about 13% are aged between 20 and 30 and 6% are aged 75 or over.

Berkshire has more residents from Black (African, Caribbean or other), Indian, Pakistani, Bangladeshi, Chinese, or other minority ethnic groups (including other White ethnic groups) than the other counties, accounting for 15% of its population. Buckinghamshire has 11.4% Black and minority ethnic citizens, Oxfordshire 8.8% and Northamptonshire 6.7%.

In general, the regional population is healthier and less deprived than those living in many other parts of England. There are, however, pockets of deprivation in some parts of the Region and there are higher rates of diseases (e.g. breast cancer) associated with a higher social class distribution.



Cancer care facilities

Cancer services are organised by the Thames Valley Cancer Network for Berkshire, Buckinghamshire and Oxfordshire, and by the Leicestershire, Northamptonshire and Rutland Cancer Network for Northamptonshire. Within the area there are eight hospitals providing cancer care; three of these have radiotherapy facilities.

PSA (prostate specific antigen) testing has been common within the area since the early 1990s, but there are currently no routine data on levels of testing.

Registry structure and methods

The registry is centrally funded by the Department of Health. There are 15 full-time-equivalent staff members, with 5.5 in the registration section, 4.5 information analysts, 4.0 IT and business support, and a part-time Medical Director.

Cancer registration data have been collected on a regional basis since 1952. The registry is notified of cases by histopathology and cytopathology laboratories and medical records departments. Death certificates where cancer is mentioned are also passed to the registry from the Office for National Statistics (ONS). In addition, all registered cancer patients are flagged on the NHS Cancer Register to ensure that the local registry is informed of deaths among the registered population, including those from causes other than cancer and those occurring outside the region. There is collaboration with specialist registers (e.g. Childhood Cancer Research Group, Oxford Regional Leukaemia Register) and directly with clinicians to collect certain types of data.

The registry collects data on all malignant tumours, *in situ* neoplasms and certain benign tumours. An abstract of each tumour record is passed to ONS for inclusion in the National Cancer Registration Scheme. Information on non-residents treated within the Oxford Region is passed to the appropriate regional registry and is part of a reciprocal arrangement.

Until 1992, the process of registration was entirely manual. In September 1992, a Hewlett Packard 9000 RISC minicomputer system was installed running Unix, Informix, SQL and the C-Cris 1 Cancer Registration System. Currently electronic versions of pathology reports (abstracted by identifying all cancer SNOMED codes) with demographic details separately identified are received from all laboratories. Electronic downloads from Casemix/Patient Administration Systems and from Oncology systems are received from all provider sites. Ox-link record matching software is used to distinguish new registrations from amendments or non-registrable cases. Demographic details of new registrations are added automatically to the file. Clerks then add the diagnosis and treatment details.

Interpreting the results

All borderline malignant tumours were included in downloads from anniversary year 1993. Prior to this, apart from one or two tumour types (i.e. polycythaemia vera) with a fifth digit of 1 (borderline malignant), they were not collected.

There were significant changes to the UK practice of bladder coding from anniversary year 2000. This meant that bladder cases diagnosed as papillary non-invasive transitional cell carcinoma—grades I and II—which had previously been coded as malignant (pathology reports also reported them as 81303 - malignant) were now to be coded to a borderline code. This had quite an impact in the number of malignant cases reported; the malignant cases reduced in number and the borderline cases rose significantly. It was also agreed at the same time that papillary non-invasive transitional cell carcinoma grade III was to be coded to ‘in situ’.

Use of the data

The Oxford Cancer Registry is now part of the Oxford Cancer Intelligence Unit (OCIU). OCIU is responsible for cancer registration, for providing a cancer information service, managing quality assurance and evaluation of the breast and cervical screening programmes in the Region and undertaking and contributing to programmes of clinical audit and research. The registry contributes to the annual UK Association of Cancer Registries review of the completeness and accuracy of registry data.

Source of population
Mid-year estimates based on censuses in 1991 and 2001 (Office for National Statistics).

Multiple primary rules used
IACR rules (2004) on CI5 IX period.

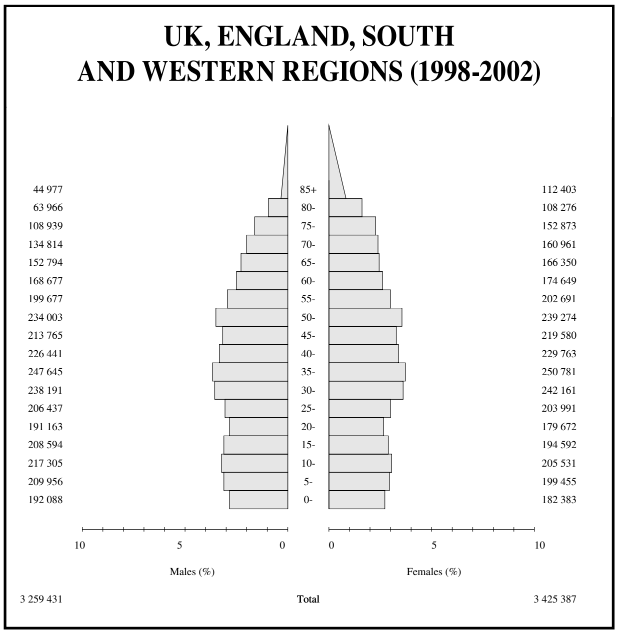
UK, England, South and Western Regions

Registration area

The South West Cancer Intelligence Service (SWCIS) collects data on all cancers and suspected cancers for the South West region of England, including Hampshire and the Isle of Wight. In all, it covers an area some 300km by 100km, with a coastline of over 1400km. The population of 6.8 million is nearly all white Caucasian and predominantly Christian, with an approximate 60/40% split between urban/suburban and rural. A large proportion of the population (approximately 20%) are retired.

Cancer care facilities

The SWCIS area is served by 12 main hospitals, within which there are seven designated cancer centres. There are a further eight regional hospitals with Accident and Emergency (A&E) departments and significant treatment facilities, as well as numerous small hospitals for minor injuries and recuperation.


UK, ENGLAND, SOUTH AND WESTERN REGIONS (1998-2002)

Registry structure and methods

The SWCIS is one of nine regional registries in England. It is split between two sites, one in Bristol (mainly data users) and one in Winchester (mainly registration and IT). The SWCIS is funded by government, through the Department of Health.

In 2005 the SWCIS merged with the South West Public Health Observatory (SWPHO). The aim of the SWPHO is to provide a seamless public health intelligence service for the region. The SWCIS employs 17 registry staff, 4 information analysts, 5 clinical audit team members, and 5 Network Liaison Officers who provide an important link between the registry and cancer networks. Their work is supported by Business Management, IT and Publications and Communications teams who work across the whole organisation.

The SWCIS collects its data from three principal sources: Hospital Patient Administration Systems (Clearnet); pathology laboratory reporting systems, and the national deaths database. These are accessed via electronic capture and processing with manual intervention to resolve complexity or data conflict. Over 75% of records are initially electronically captured with more than two independent sources usually involved. Eight subsidiary data sources include: private hospitals, military hospitals, cancer screening centres, follow-up with consultants, audit databases, other cancer registries, cancer/treatment centre databases and national research centres.

Interpreting the results

The coverage provided by the above range of sources, and verified by checks made through audit, is over 99%. Death Certificate Only registrations are less than 3%.

The UK runs screening services of more than ten years standing for cervical and breast cancer.

The registry has only recently started registering skin cancers of basal cell carcinoma (BCC, C44) due to the large numbers and limited interest in this type of cancer in the past. C44 were not collected systematically until 1998. For BCC and Squamous Cell Carcinoma (SCC) only the first primary diagnosis is registered. Cervix *in situ* D06 is incomplete for all areas. Registration of D45 is incomplete until 2001/2002. Bladder C67/D41 coding was changed in 2000. Some 80% of cancer registrations are supported by pathological confirmation. The incidence of prostate cancer has risen dramatically in parts of the registry area since 2001. This has largely been attributed to increased PSA testing.

Use of the data

There are five principal ways in which our data are made available:

The SWPHO website (www.swpho.nhs.uk). This site is accessible to all for epidemiological statistics of the important cancers and information on cancer epidemiology.

An ad-hoc information request service. Each year the SWCIS deals with over 200 information requests by phone, email, fax or letter from a wide range of health professionals and others. Regular users of the service are strategic health authorities, consultants, medical students, clinical audit, research bodies and the media.

To government via data exchange. A regular download of new and updated registrations is sent to the National Registry (ONS) for Government publication.

Publications. Cancers of special interest, patterns of treatment, and health service facility usage are regular topics of reports.

Collaborative research. The SWCIS works with a variety of partners including Cancer Networks on a range of topics to produce varied outputs including audit, new databases, follow-up studies and treatment effectiveness have all been covered in recent years.

Source of population

Mid-year estimates based on censuses in 1991 and 2001 (Office for National Statistics).

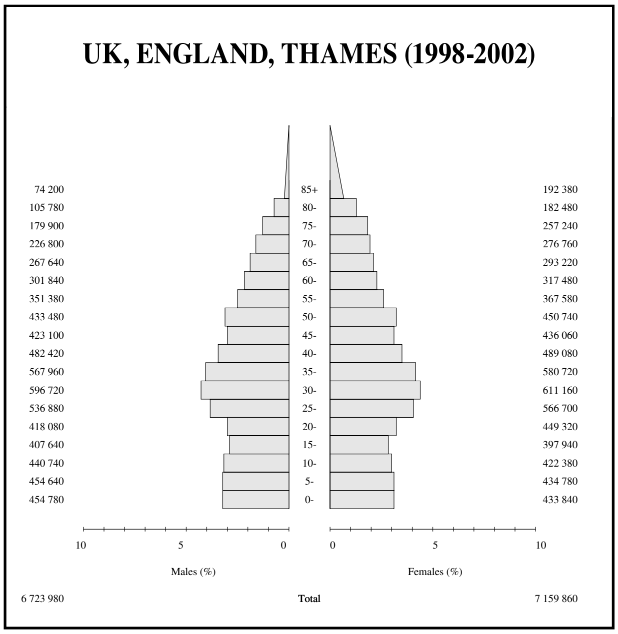
Multiple primary rules used

UKACR rules (1998).

UK, England, Thames

Registration area

The Registry was founded in 1958 as the South Metropolitan Cancer Registry, became population-based in 1960, and was renamed the South Thames Cancer Registry in 1974. Until 1984 it covered the South East and South West Thames Regional Health Authority areas (the South Thames Health Regions), with a population of approximately 6.8 million. In 1985 the Registry expanded to include the North Thames Health Regions, becoming the Thames Cancer Registry (TCR) and covering, in 2000, a population of approximately 14 million across the counties of Hertfordshire, Essex, London, Surrey, Sussex and Kent. Data in this volume cover this population, and have been submitted for diagnosis years 1985–2002. Previous volumes have covered the South Thames Health Regions only.


UK, ENGLAND, THAMES (1998-2002)

The Registry region includes some of the most affluent areas in England, and also some of the most deprived. London has an ethnically diverse population. In the 2001 census, 17% of the TCR population were not classed as white, compared with 9% in England.

Cancer care facilities

The majority of cancer patients are treated within the National Health Service (NHS). The Registry region is covered by 13 NHS Cancer Networks and more than 50 NHS secondary and tertiary care trusts. The Cancer Networks co-ordinate cancer care.

Most patients are diagnosed and treated in a secondary care trust. Patients with rare cancers and those requiring specialised care are referred to a tertiary care trust. There are 22 radiotherapy centres in the area, 19 NHS and 3 private.

Registry structure and methods

The Registry is located on the Guys Hospital campus at London Bridge, and is a department in King's College London School of Medicine. It is funded through a contract with the Regional Director of Public Health in London.

The Registry has approximately 70 staff. Thirty mobile staff actively abstract registration information from hospital medical records. The other 40 staff, at the London Bridge office, perform data entry, computing, quality assurance, analysis, reporting, research and management functions.

Principal sources of information on cancer cases are pathology reports and information systems, paper medical records, hospital patient information systems and death certificates.

Death certificates are provided electronically to the Registry by the Office for National Statistics. Certificates are provided for registered patients, and for all people dying in the Registry's catchment area from or with cancer.

The Registry collects patient identifying information. Special provision within the Health and Social Care Act 2001 enables the Registry to continue this practice without the direct consent of patients. Cancer is not a notifiable disease in the UK.

A wide range of data validation checks are applied by the Registry's computerised registration system at the time of data entry/import. Automated retrospective validation checks are made daily. Patient deduplication is done annually. The Registry regularly reports and monitors the stability of its case ascertainment and data and process quality indicators. The Registry participates in the quality assurance activities of the United Kingdom Association of Cancer Registries, which formally evaluate the Registry's stability, data quality and completeness.

Interpreting the results

Previous volumes have reported incidence in the South Thames Health Regions only. The data in the present submission cover the residential population of South East England (the counties of Hertfordshire, Essex, London, Surrey, Sussex and Kent) in the period 1985–2002. This is the territory of the (now historic) North and South Thames Health Regions.

There are organised national screening programmes for breast and cervical cancer. The Registry exchanges data with the breast-screening programme. Prostate-specific antigen testing is common in the Registry's population, and this has led to increased rates of prostate cancer, particularly in men under 70 years of age.

Use of the data

A range of reports are provided for health organisations in the Registry's region. Research activity and output in the Registry have increased in recent years. The Registry contributes data to a regional Cancer Information Service available online to NHS users. The Registry recently prepared national long-term cancer incidence predictions for the Department of Heath. For further information, see http://www.tcr.org.uk/.

Source of population

The population table has been extracted from national population files produced by the Office for National Statistics (ONS). It details the population of the Thames Cancer Registry diagnosis years 1985-2002 catchment area for the calendar years 1985-2002. National censuses were held in 1981, 1991 and 2001. The 1991 and 2001 populations in this table are from the censuses in those years. The populations for the other years in the file are mid–year estimates based on census data.

Multiple primary rules used

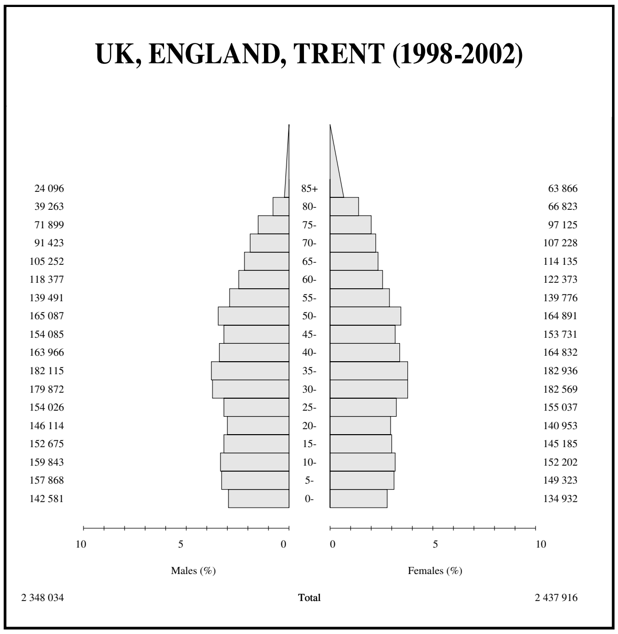
IACR rules (2004) on historical data.

UK, England, Trent

Registration area

The Trent region covers the counties of Derbyshire (except its north-west tip), Leicestershire, Rutland, Lincolnshire, Nottinghamshire and South Yorkshire, an area of 14 763 km^2 with a resident population of 4.8 million. The area is served by 11 Acute Trusts, 12 Primary Care Trusts and three medical schools (Leicester, Nottingham and Sheffield). It spans two Government Office Regions (Yorkshire and the Humber, and East Midlands) and is the lead Cancer Registry for providing information to four Cancer Networks (North Trent, Mid Trent, Derby/Burton, Leicestershire, Northamptonshire and Rutland). Cancer Centres are located in Derby, Leicester, Nottingham and Sheffield, where radiotherapy and chemotherapy services are available. United Lincolnshire Hospitals NHS Trust is a cancer unit with radiotherapy services.

Despite variations within the region, the overall Trent population profile is comparable with that of England. Forty percent of Trent local authorities are in the two most deprived quintile groups for the whole of England, compared with 35% in the two least deprived quintile groups. Just less than 75% of the resident population live in urban areas. The ethnic profile of the population is predominantly White (93.7%), with sizeable numbers from Asian ethnic groups (3.9%), most notably Indian (2.5%).



The area covers a variety of industry. The decline of the coal and steel industries over the last thirty years has led to considerable economic re-development with heavy industry being replaced with light engineering and service industries. Textiles and the pharmaceutical industry also have a strong hold in the region. Many of the rural areas support farming, food production and tourism.

Routine breast and cervical screening programmes operate in the Trent Region. Roll-out of the regional bowel cancer screening programme commenced in March 2007 at the Derbyshire Screening Centre, and completion is planned for 2009. The NHS Prostate Cancer Programme was launched in 2000 and testing for prostate cancer is now available on request to men aged over 50 years on an informed choice basis.

Registry structure and methods

Cancer registration in the Trent region began in 1955. Since then there have been a number of significant changes and reconfigurations that have resulted in the organisation we see today: Most recently, in 2003, the Registry moved to the current premises in Fulwood, Sheffield and in 2005 benefited from a merger with the East Midlands Public Health Observatory giving greater opportunities for joint working and significantly expanding the type of work/projects the registry is able to undertake.

Trent Cancer Registry collects a common minimum dataset on cancer. Cases diagnosed in hospitals (inpatient and outpatient) are notified to the registry electronically, including details taken from pathology reports. Other cancer registries notify the registry of Trent residents treated outside the region. Copies of Death Certificates are routinely received from the Office for National Statistics (ONS) for all cases where cancer is a cause of death. When the cause of death is not cancer related, the registry is notified by the National Health Service Central Register, where all registered cancer patients are flagged.

On receipt, data are validated using extensive edit procedures (incorporating those of the ONS), and checked for duplicate registrations and identification of patients with multiple primaries. Formal evaluation of the completeness and accuracy of information recorded by Trent Cancer Registry is ongoing as part of the UKACR National Cancer Peer Review Programme. This aims to improve the processes, timeliness, quality and provision of cancer information.

The current database holds records from 1966 comprising more than 900 000 individual registrations from across the Trent Region, with approximately 35 000 new registrations (malignant and non-malignant) each year. At intervals, new registrations are abstracted and sent to ONS to update the national system.

Use of the data

Data are used for a variety of purposes, in particular, responding to local health requests for information to support the effective provision of cancer services, use in studies both locally and nationally, providing information to support genetic counselling service enquiries, and responding to ad hoc requests as appropriate.

Some statistics, further details and also information about reports and other publications, can be found on the Trent Cancer Registry Website: www.trentcancer.nhs.uk

Source of population

UKACR Populations Dataset Version 3.

Multiple primary rules used

UKACR rules (1998).

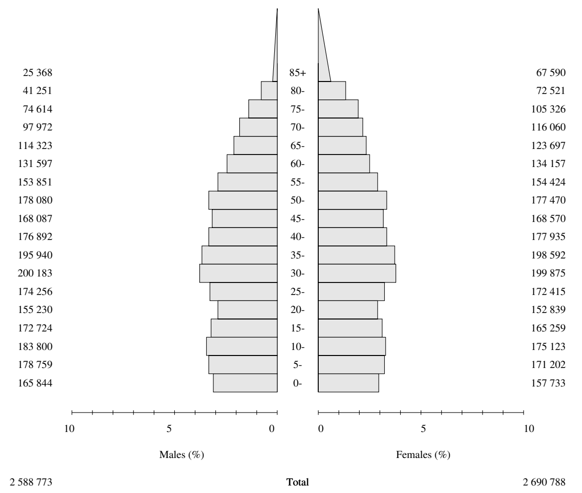
UK, England, West Midlands

Registration area

The West Midlands registration area covers a population of 5 300 000 people in 2002, just over 10% of the total population of England. There are marked differences in population density across the region, with very densely populated urban areas and more sparsely populated rural areas. Non-white residents make up 11% of the total West Midlands population, with the largest ethnic groups being Indian (3.4%), Pakistani (2.9%) and Black Caribbean (1.6%) (2001 census). The percentage of non-white residents is considerably higher in some areas of the West Midlands such as Birmingham (30%), Wolverhampton (22%), Sandwell (20%) and Coventry (16%).

In April 2002, the West Midlands region was divided into three Strategic Health Authorities, but in October 2006 these were amalgamated into single Strategic Health Authority covering the whole region. There are five cancer networks covering the West Midlands population. Three (Arden, Pan Birmingham and the Greater Midlands Cancer Networks) are entirely contained within the West Midlands; the Derby/Burton and 3 Counties Cancer Networks also include residents of other registration areas.

UK, ENGLAND, WEST MIDLANDS (1998-2002)



Cancer care facilities

There are 18 acute hospital NHS Trusts within the West Midlands, all of which diagnose and treat cancer patients. Five of these are cancer centres providing radiotherapy. A relatively small number of cancers are diagnosed in private hospitals, nursing homes and hospices. The WMCIU receives diagnostic and treatment information from all of these organisations.

Whilst there are no routine data available on the rates of PSA testing in the West Midlands, there has been a large increase in prostate cancer since the late 1980s, when the PSA test was made widely available. Furthermore, this increase is much greater in the most affluent men.

Registry structure and methods

Cancer registration in Birmingham dates to 1936. Originally based on a single hospital, its scope was gradually extended until by 1957 it included the whole region.

The WMCIU employs 23 staff in the cancer registration and data quality section. Four teams of tumour registrars and cancer registration clerks are responsible for processing the data received from NHS and private hospitals, nursing homes and hospices in a particular geographical area. Each team leader also has a specific area of responsibility; cancer registration, data quality, training and records management. The research and information team consists of 7 staff and the computing and automated cancer registration teams of 5 staff. A further 6 staff provide business, administrative and secretarial support. The WMCIU is funded, as are all English cancer registries, via top-sliced, earmarked funding from the Department of Health.

Cancer registration is not a legal requirement in the UK at present. However, regulations passed under section 60 of the Health and Social Care Act 2002 permit cancer registries to collect identifiable patient data assuming the implicit consent of the data subjects. Cases are mainly registered following receipt of information from clerical staff at individual hospitals in the form of relevant histopathology reports and clinical case notes, such as radiotherapy reports. Some hospitals send this information in electronic format as a single patient record. The information collected includes demographic details, tumour characteristics, details of the involved clinicians and hospitals, and the nature of treatment. Copies of death certificates are routinely received from the Office for National Statistics (ONS) for all cases mentioning cancer. If no further information is received after six months, additional details are sought from Primary Care Trust medical records departments (to whom all general practitioner records are returned after a patient's death) and hospitals are contacted to obtain relevant details. Non-cancer deaths are provided routinely by the National Health Service Central Register where all registered cancer patients are flagged. Active follow-up of patients is carried out for specific research studies (particularly survival studies that include extra-regional cases) but not routinely.

In 1994, the WMCIU's existing tumour-based records were converted to a patient-based system in which all patients have a unique identifier and individual patients can have several tumours each with a unique tumour number. This increased the ease and speed of registration and facilitated more complex validation and data-quality checks in line with IARC and ONS recommendations.

Use of the data

The WMCIU's database is used for routine data provision and for clinical audit and research purposes. Since 1995, data collected by the WMCIU have been used to assist in planning and monitoring the efficacy and cost-effectiveness of cancer services. The WMCIU is also involved in the EUROCARE study and contributes data to EUROCIM. The April 1996 incorporation of the NHS Breast and Cervical Screening Quality Assurance Services into the existing structure facilitated the synergistic combination of cancer registration and screening databases. The first major outcome of this has been the establishment of routine systems for obtaining breast and cervical cancer screening histories for all women in the screening age band, including the determination of interval cancer and non-attender rates.

In 2001, the WMCIU launched the electronic Cancer Information Service (CIS), providing a powerful tool to enable health workers connected to the NHS Net to access cancer data from their own PC. Modules available include cancer incidence, mortality and survival data, analyses of cancer registration data quality and outcome measures relevant to the quality assurance of the NHS Breast and Cervical Screening Programmes. The WMCIU has a web site (www.wmpho.org.uk/wmciu/) from which general information on cancer incidence, mortality and survival can be obtained.

Source of population

Population estimates are based on the 2001 Census and built up from Census Area Statistical Wards. ONS estimates have been used to estimate the populations forwards and backwards to cover the period 1998–2002.

Multiple primary rules used

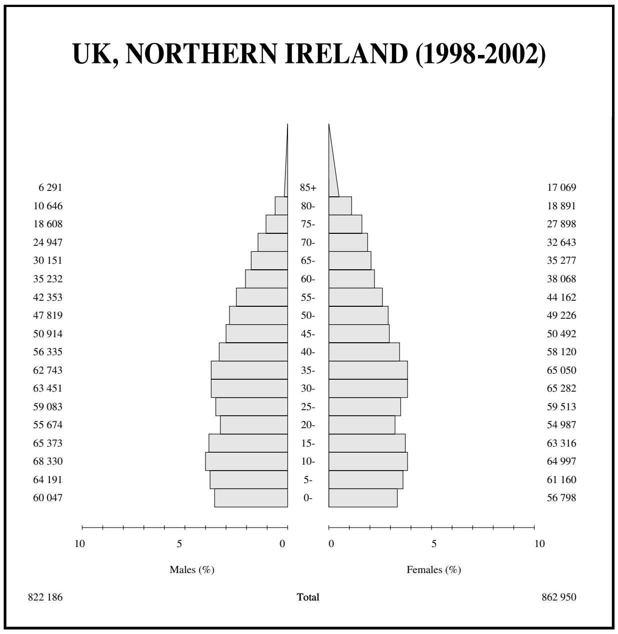
IACR rules (2004) on historical data.

UK, Northern Ireland

Registration Area

Northern Ireland consists of the six counties in the north of the island of Ireland and is part of the United Kingdom. The population of Northern Ireland was 1 689 319 at the last census year of 2001. Whereas most of the population is rural, there are two major urban areas situated around the cities of Belfast and Londonderry. Most of the heavy industry is located in the two urban areas. The population is relatively racially homogeneous with only a few small ethnic minorities, although there has been a recent influx of immigrants mainly from Eastern Europe.

The Northern Ireland Cancer Registry is a population-based registry that covers the entire population of Northern Ireland. Historically we have had high death rates from mesothelioma due to the shipbuilding industry in Belfast. In April 2007, a smoking ban was introduced into all work and public places.



UK, NORTHERN IRELAND (1998-2002)

Cancer care facilities

Most cancer patients are treated within the National Health Service system and even most private patients receive some of their treatment in National Health Service hospitals. Until 1 April 2007 there were 13 separate Hospital Trusts, which treat cancer patients amongst the four regional Health Boards. There is one radiotherapy department in the region, serving all cancer patients in the area. The vast majority of patients receive all their care within the region. A major re-organisation of cancer services in 1997 introduced the concept of a cancer centre and four cancer units for the population.

Registry structure and methods

The current N. Ireland Cancer Registry was established in 1994 to provide information on cancers in the Northern Ireland population for the purposes of research, education and the planning of services. The new registry, located in Queen's University Belfast, replaced an existing Department of Health and Social Services (DHSS) Registry that began in 1959. It is funded by an annual grant from the Department of Health with five yearly reviews to ensure quality and to advise on direction.

The registry uses an automated computer system with multiple sources of notification of patients with cancer. The Registry uses three main sources for registration, the Patient Administration System (PAS) used by all the Hospital Trusts, histopathology reports and death notifications. From PAS the registry obtains demographic information on individual patients along with data on their length of hospital stay and basic tumour site and behaviour information as an ICD-10 code. PAS information includes limited surgical treatment information. The tumour information is supplemented by electronic downloads from histopathology and cytopathology laboratories

The registry collects information on all neoplasms diagnosed in Northern Ireland. Some cancer-related conditions such as Barrett's oesophagus, hydatiform moles and CIN-I and CIN-II of the cervix are also recorded.

A major focus of the registry's operation work is on the verification of information from a single death certificate (death initiated cases), a single hospital admission or a single histopathology report. Registry staff examine practitioners notes for patients who have died from cancer. The staff also examines hospital records for cases identified without confirmatory histopathology or cytology. Histopathology reports are also checked for conflicting information or other possible errors.

The registry does not routinely receive tumour staging information but extracts some staging information from the written histopathology reports. Pathological staging is carried out by Registry staff on selected sites only—breast, colon, rectum, cervix, melanoma, bladder, testis and ovary. An electronic tool to facilitate clinicians staging cancer has been developed by the registry. Pilot studies indicate enhanced recording of stage. The Registry has piloted the capture of staging and other information at Multidisciplinary Team meetings, which discuss individual patient treatment plans and care.

The Registry has rigorous Quality Control and Quality Assurance programmes to ensure high levels of data completeness and accuracy. The Registry contributes annually to the UAKACR Quality Assurance Group to help monitor data quality issues. Additionally we routinely use the Flow Method for case ascertainment and yearly data re-abstraction to monitor data quality.

Interpreting the results

Population-based breast screening has been offered to all women aged 50–64 since 1993. The programme operates a three yearly recall system and was recently extended to include women up to the age of 70. Cervical screening has been available population-wide to all women over 20 since the late 1980s. PSA testing for prostate cancer has steadily risen since the early 1990s; however there are no formal guidelines at present to use this for population screening.

Use of the data

The registry not only registers all cancers in the region, but also provides a cancer information service and has a close connection with the breast and cervical screening services and the local cancer network. Registry data are routinely used by policymakers to evaluate and plan cancer services throughout the region. Registry reports on cancer survival, trends, cluster investigation and disease-specific audits are available at www.qub.ac.uk/nicr. The registry data on

Barrett's oesophagus and prostate cancer screening have formed the basis of research projects.

Source of population
2001 census. Northern Ireland Population census conducted on 29th April 2001. 1998, 1999, 2000, 2002: Mid Year population based on the results of the 1991 and 2001 censuses adjusted to take account of births, deaths and migration between Census Day and the Mid–Year date of 30th June.

Multiple primary rules used
IACR rules (2004) on CI5 IX period.

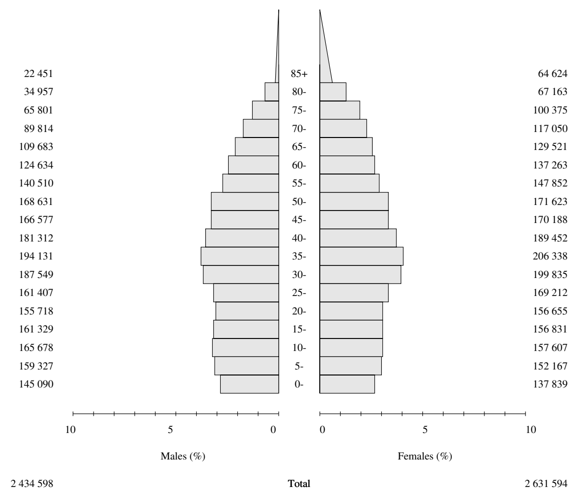
UK, Scotland

Registration area

The Scottish Cancer Registry covers the whole of Scotland, which has a population of just over five million. The majority of the population live in an industrialised belt across the centre of the country. The majority (87.15%) of the population were born in Scotland but 9.07% were born elsewhere in the United Kingdom (England, Wales, or Northern Ireland). A relatively small percentage (1.53%) were born elsewhere in Europe, and 2.25% in the rest of the world.

Cancer care facilities

The National Health Service in Scotland is funded mainly through taxation and is mostly free at the point of use. Access to hospital care is controlled by a well-developed system of primary care. Radiotherapy facilities are provided at five main centres (Inverness, Aberdeen, Dundee, Edinburgh, and Glasgow), but many patients with cancer are diagnosed and receive their primary therapy at district general hospitals. The private healthcare sector in Scotland is relatively small.



UK, SCOTLAND (1998-2002)

Registry structure and methods

The Scottish Cancer Registry forms part of the Information Services Division (ISD) of the National Health Service National Services Scotland (NHS NSS). The core registration function is funded by the Scottish Executive Health Department.

Until 1997, five regional cancer registries carried out registration, and the role of the national registry was limited to coordination, data collation, analysis and publication. In 1997, the national registry assumed responsibility for all aspects of registration and established a network of outposted, peripatetic cancer registration officers based in the main hospitals. Currently the registry is staffed by a medical director, a national coordinator, six central registry staff (two of whom work part-time), and 24 outposted staff (three of whom work part-time).

Cancer is not a notifiable disease in Scotland. Until 1997, the regional registries relied mainly on hospital inpatient sources, pathology records and death records to identify registrations. Since reorganisation, potential registrations are identified from four main computerised sources: hospital discharge records, oncology records, pathology records and death records. Information from these and other, non-computerised sources is linked to create provisional registrations that are made available to the outposted cancer information officers. By referring to medical records, the outposted staff validate the provisional registration and abstract additional information that cannot currently be collected electronically. The registry has an active programme of quality assurance.

Interpreting the results

The registry introduced ICD-10 and the second edition of ICD-O for diagnostic coding of patients diagnosed on or after 1 January 1997. Previously records were coded to ICD-9 and morphology to the first edition of ICD-O. The registry dataset was also expanded in 1997 to include most valid basis of diagnosis, method of first detection, grade of differentiation, stage of disease (for colorectal, female breast and cervix cancers), treatment details and entry to any clinical trial.

Cervical screening began in parts of Scotland in the early 1960s, but coverage was uneven until a computerised call-recall system was introduced in the late 1980s, offering cervical smears to eligible women in the age group 20–60 every three years. A national breast screening programme was phased in to Scotland in the late 1980s for all women aged 50–64 years every three years, and older women on demand. However, beginning in 2003/04, the age range for invitation was extended to include women up to the age of 70. In April 2000, in three (out of 15) Scottish health boards, a colorectal cancer screening pilot project was established to assess the feasibility of introducing a national screening programme based on offering faecal occult blood testing to individuals aged 50–69 every two years.

The prostate specific antigen (PSA) test was introduced to Scotland in 1989, and use of the test has increased strikingly since then. Although screening for prostate cancer is not currently recommended in Scotland, there is some evidence of differing thresholds for application of the PSA test since there is now considerable variation in incidence across the 15 Scottish health board areas despite much less variation in mortality.

In adults, the prevalence of smoking is estimated to have fallen from 46% in 1976 to 28% in 2002, although serious concerns remain about the prevalence of smoking among teenagers in Scotland. Alcohol consumption has increased greatly in Scotland since the 1950s. The diet in Scotland is widely regarded as unhealthy, and there is no evidence of any substantial change overall in fresh fruit or vegetable consumption since the early 1950s.

Use of the data

The Scottish Cancer Registry publishes data regularly on incidence, and periodically on survival. Increasingly, information is being made available on the internet (http://www.isdscotland.org/cancer). *Ad hoc* analyses of the data are carried out in response to many requests for information from a wide variety of data users. The Scottish Cancer Registry is involved in several major studies, both in-house and collaborative. The registry data are used for a wide range of purposes including public health surveillance, needs assessment, planning and commissioning of cancer services, evaluating the impact of interventions on incidence and survival, clinical audit and health services research, epidemiological studies aimed at determining the causes of cancer, and providing information to support a range of functions including genetic counselling and health education.

Source of population
Official estimates: Mid–year (30 June) population estimates. General Register Office Scotland (GROS): (mid–year 2002) http://www.gro–scotland.gov.uk/statistics/library/poptest/02–mid–year–tables/index.html.

Multiple primary rules used
IACR rules (2004) on historical data.